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University of Glasgow | Institute of Health & Wellbeing

**An Online CBT-based Life Skills Course for Carers of Children  
with Chronic and Life Limiting Conditions: a Feasibility Trial**

**And Clinical Research Portfolio**

**Volume 1**

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## **Chapter 1: Systematic Review**

### **The Efficacy of internet-based Psychological Interventions in Reducing Carer-giver Stress in Carers of Children with Chronic Medical Conditions: a Systematic Review**

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(See Appendix 1.1)

## **ABSTRACT**

**Background:** Caring for a child with a chronic medical condition can result in high levels of carer stress. Psychological interventions for caregivers can enhance caregiver wellbeing. This systematic review aims to review the evidence of efficacy for internet-based interventions for carers of children/adolescents with chronic health conditions.

**Method:** Five electronic databases were searched for trials examining the efficacy of internet-based interventions for caregivers of children/adolescents with chronic medical conditions. Studies were limited to those published between May 2003 and May 2018. Narrative synthesis was used to combine the results of all included studies and treatment effect sizes were calculated for individual studies to estimate the overall efficacy.

**Results:** Eleven studies were identified. Studies took places in USA, Canada, Sweden and Germany. All used convenience participant samples of caregivers of clinic attenders. A range of internet-based interventions were trialled targeting caregivers of young people with a variety of medical conditions. All studies reported significant treatment effects on at least one outcome of caregiver stress with studies reporting treatment effects which ranged from small to large.

**Conclusions:** Internet-based interventions were mostly effective in reducing elements of caregiver stress. The review highlights the need for further high-quality trials offering internet-based interventions to caregivers of children/adolescents with chronic medical conditions to further assess their potential effectiveness, explore different technological delivery methods and investigate their acceptability to caregivers.

**Key words:** Internet interventions, CBT, caregivers, carer stress, children, adolescents, chronic conditions, systematic review.

## **INTRODUCTION**

Over 6 million adults in Britain currently provide care to individuals with physical/mental health conditions (Office for National Statistics, 2006) and 8% of caregivers look after disabled children under the age of 18 (NHS Information Centre for Health and Social Care, 2010). Caring for a child with a chronic medical condition can significantly affect caregiver well-being (Eccleston, Palermo, Fisher & Law, 2012) with higher levels of emotional distress (Barlow & Ellard, 2006) and parenting stress (Cousino & Hazen, 2013) reported.

Recent reviews of psychological interventions for caregivers of children/adolescents with chronic illness reported that problem-solving based therapy (Eccleston et al. 2015) and cognitive behavioural therapy (CBT) can have a positive impact on reducing caregiver stress. Unfortunately, help-seeking barriers (Keeley and Clarke, 2002) can prevent caregivers from accessing appropriate supports. A recent review of consumer health information technology to support caregivers of individuals with chronic illnesses highlighted that online modalities which supported caregiver interaction were highly used and valued (Dyer et al. 2012). Also, in wider mental health services, computerised Cognitive Behavioural Therapy (cCBT) is a recommended treatment option for depression and anxiety disorders (NICE, 2009, 2011). This suggests that internet-based interventions may be potentially both effective and acceptable to caregivers of children/adolescents with chronic illness in supporting them with carer stress/burden. A recent systematic review of internet-based interventions for

caregivers of individuals with chronic conditions (Hu et al. 2014) showed evidence for the effectiveness of the internet as a modality for providing effective support. No review to date has, however, specifically reviewed the content and effectiveness of internet-based psychological interventions for caregivers/parents of children/adolescent with chronic conditions.

## **OBJECTIVES**

The rationale for the current review is to contribute to the evidence on caregiver stress and burden. Reductions in caregiver stress can increase caregiver quality of life as well as the quality of care they provide to others (Eccleston, Palermo, Fisher & Law, 2012). There is a need to better understand the potential effectiveness of the internet as a modality to provide support for carers of children/adolescents with chronic medical conditions.

The aim of this review is to systematically review evidence of efficacy for internet-based interventions for caregivers of children/adolescents with chronic health conditions. Specifically it will explore:

- What internet-based interventions, aimed at reducing caregiver stress, have been developed?
- What additional supports the interventions offer other than online material?
- Which chronic conditions interventions are tailored for?
- How effective the interventions are in reducing caregiver stress.
- Which clinically relevant outcomes have been measured?
- The quality of the research investigating their use.



## **METHODS**

The following systematic review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA; Moher et al. 2009). Searches of the Cochrane Database of systematic reviews and the Database of Abstracts of Reviews of Effects (DARE) were completed to ensure no previous literature reviews had been conducted on the chosen topic.

### **Inclusion Criteria**

Studies which met the following criteria were included within the systematic review:

- (i) Population: Adult ( $\geq 18$  years of age), non-professional (informal) carers of children/young people with chronic health conditions.
- (ii) Intervention: internet-based psychological interventions for caregiver use designed to reduce caregiver stress or burden / increase quality of life.
- (iii) Comparator: No control group, Treatment as usual (TAU) control or alternative intervention comparison.
- (iv) Outcome: Objective formal measures of caregiver stress/burden, psychological distress or quality of life.
- (v) Study Design: Randomized controlled trials (RCT), open label trials or pilot studies published in English, in peer reviewed journals.
- (vi) Setting: Interventions administered solely online.

## **Exclusion Criteria**

- (i) Studies which offered intervention for carers of children/young people with a mental health difficulty.
- (ii) Reviews, dissertations, book chapters, conference abstracts, study protocols.
- (iii) Non-peer reviewed articles.
- (iv) Articles not published in English.
- (v) Studies which did not include a formal measure of carer wellbeing, stress or quality of life.
- (vi) Studies which did not evaluate truly internet or web-browser based interventions including: DVD, videophone technology or purely videoconferencing interventions.
- (vii) Studies which provided internet based education or disease information only without any psychological intervention or guided self-help component.
- (viii) Discussion forums (e.g. carer chat-rooms/online support groups).
- (ix) Feasibility studies which did not report pre and post outcome measures.
- (x) Studies which only evaluated improvements in child wellbeing/disease outcome.

## **Search Strategy**

The following databases were searched in May 2018 for relevant research studies published between May 2003 and May 2018 which met the above criteria: EMBASE (Via Ovid SP), MEDLINE (Via Ovid SP), PsychINFO (Via EBSCOhost), CINAHL (Via EBSCOhost) and Web of Science. In order to identify any missed

articles the references lists of key review articles (Hu, C. et al, 2014; Law et al. 2014) and all of the included studies were searched by hand for other eligible studies. The contents lists of two relevant journals (Journal of Medical Internet Research and Internet Interventions) were also searched by hand for further relevant articles published in the past 3 years (May 2015 to May 2018). Any research protocols/conference abstracts were followed up to establish if they had led to any subsequent publications. Only articles with full available data were included within the review.

The search algorithm was:

caregiver\* OR famil\* OR parent\* OR mother\* OR father\*

AND

Technolog\* OR internet\* OR computer\* OR electronic\* OR Software\* OR Web\* OR Online\* OR Wireless\* OR Wi?fi\*

AND

Child\* OR teen\* OR Adolescent\* OR Paed\* OR Pediatric\*

AND

Evaluation OR intervention OR trial OR pilot study

(See Appendix 2.1 for example search strategy)

All search terms were combined using Boolean operators 'AND' and 'OR'. Truncations (symbolised by an asterisk) were used with search terms to ensure that all search term endings following the truncation were identified in each database search.

Search terms were developed based on previous systematic review exploring internet based interventions for carers (Hu et al. 2014) and following discussion with a librarian.

All duplicate results between databases were identified and then excluded. Titles of the remaining articles were screened by the primary researcher. Any that did not meet the inclusion criteria were excluded. Abstracts were then assessed against the inclusion/exclusion criteria by the author. Full articles were retrieved and assessed for eligibility when it was unclear if the study met the inclusion criteria from the abstract alone.

### **Quality Rating**

All included studies were assessed for quality using the Clinical Trial Assessment Measure (CTAM; Tarrier and Wykes, 2004); a reliable and valid quality measure. Studies were evaluated for quality against six subscales including; sample size, recruitment and allocation, assessment of outcome, control groups, analysis and description of active treatment. A score out of 100 was then calculated based on these six subscales. To assess inter-rater reliability for quality rating, an independent reviewer (EB) rated all the included studies. Discrepancies in quality rating were discussed and studies reviewed until consensus was agreed (See Appendix 2.2).

### **Data Extraction**

Data from the included studies was initially synthesis through tabulation and qualitative description of the research data. The data extracted included participants (number, gender, mean age, type of chronic condition of care

recipient), intervention description, intervention and control/comparison groups, intervention duration, outcome measures and study results. Within and between-group effect sizes for online interventions effects were calculated when data was available.

## **RESULTS**

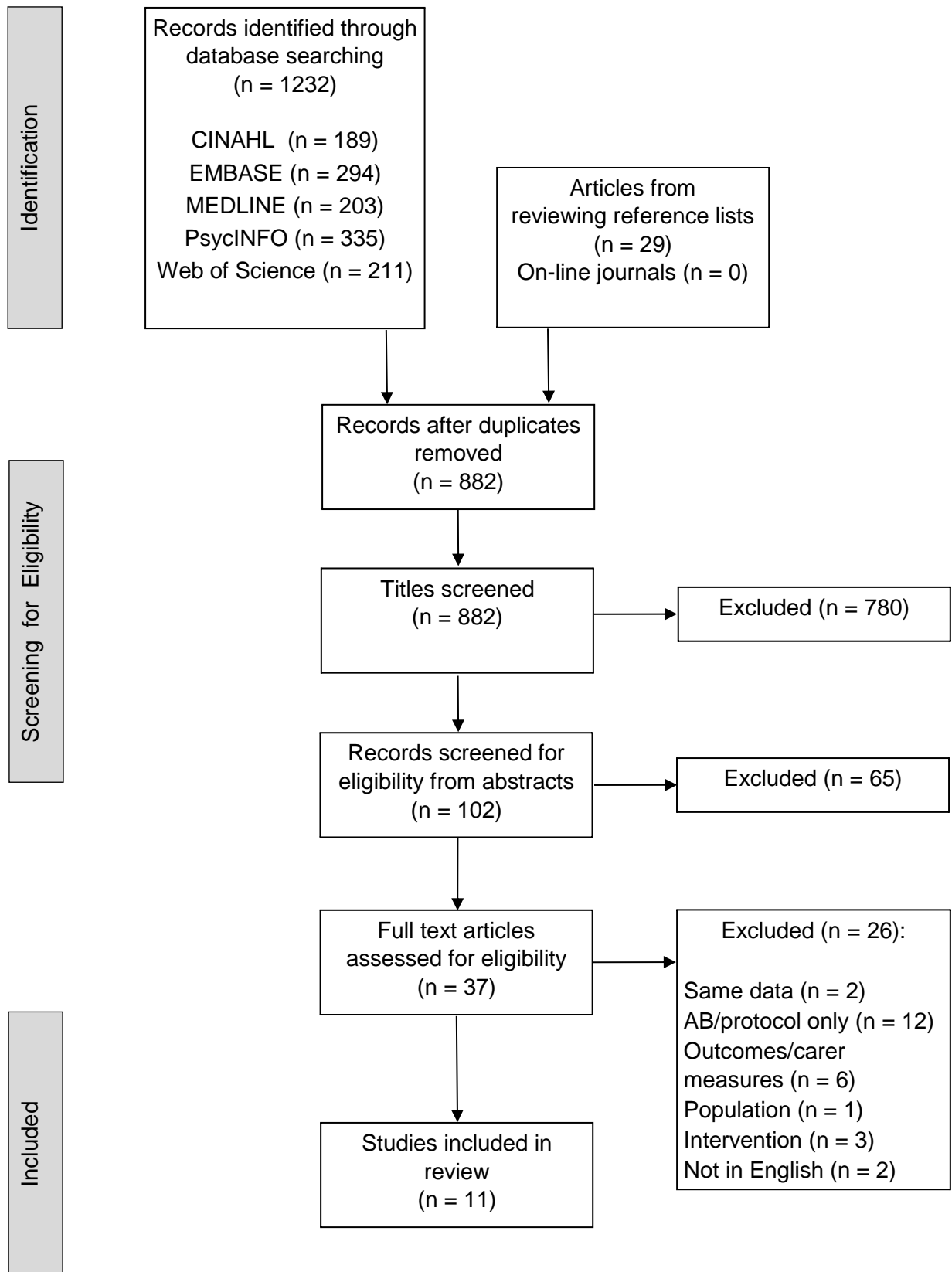
A total of 1261 references were identified, with 882 screened and 37 full articles assessed for eligibility. Figure 1 includes a PRISMA flow diagram demonstrating the systematic search process. Eleven studies met inclusion criteria. Data from one study was supplemented by a companion article (Cernvall et al. 2017) which included follow-up data.

### **Overview of included studies**

#### **Interventions**

Therapeutic approaches utilised within the interventions varied including; internet-based family problem solving (Studies 4, 8, 9, 10 and 11), self-guided internet-based CBT (Studies 1 and 3), web-based cognitive writing therapy (Study 2) and parent interaction therapy with information on caregiver well-being/self-care. All interventions were delivered online (See Table 3 for details). The number of sessions offered across the different interventions ranged between 7 and 16 with the duration also varying (range: 6 weeks - 8 months). Five interventions were targeted specifically at caregivers (Studies 1, 2, 5, 6, and 7), whereas the remaining six were designed for both caregiver and care recipient use (Studies 3, 4, 8, 9, 10 and 11).

**Figure 1:** PRISMA flow diagram illustrating search process



**Table 1:** Description of internet-based interventions.

<b>Authors</b>	<b>Intervention description</b>	<b>Duration</b>
1. Cernvall et al. (2015)	Internet-based guided self-help programme. Content based on CBT principles. 9 Modules. Intervention material accessed via an online web-portal. Participants completed one module a week.	10 weeks
2. Fidika, A. et al. (2015)	WEP-CARE - Web-based, cognitive writing therapy programme. 3 treatment components: i) Exposure to thoughts associated with anxiety, ii) Sharing responsibility for the treatment of the child, iii) Increasing self-care. One standardised writing homework assignment per week for 9 weeks.	3 to 4 months
3. Palermo, T. et al. (2016)	Web-MAP2 - Internet-based CBT self-help programme including: education about chronic pain and pain behaviours, training in behavioural and coping strategies, relaxation strategies, behavioural activation and parental communication strategies. 8 modules for parents and 8 modules for adolescents. 1 module per week. 6 homework assignments to complete.	8 to 10 weeks
4. Petranovich, C. et al. (2015)	Counsellor-assisted problem-solving (CAPS) - online family problem-solving intervention, training in communication skills, self-regulation and anger management. Initial home visit to agree goals. Each session consisted of a didactic on-line module (7 modules in total) followed by a video-conferencing session with a therapist to practise problem-solving techniques.	6 months
5. Raj, S et al. (2015)	I-InTERACT programme - a web-based intervention to support parents of children with TBI. Included; elements of parent/child interaction therapy, training in parent stress management/ anger control and education about the consequences of paediatric TBI. 10 core sessions, 7 supplemental sessions. Each session consisted of a didactic online module followed by a video-conferencing session with a therapist to practice skills with live coaching via earpiece. Sessions initially completed weekly then bi-weekly.	4 to 6 months
6. Raj, S et al. (2018)	I-InTERACT programme- as outlined in Raj et al. (2015) above. I-InTERACT Express – abbreviated version of I-InTERACT. 7 sessions without the option of supplemental sessions.	6 months

Authors	Intervention description	Duration
7. Sveen, J. et al. (2017)	Internet-based self-help programme - 6 modules, 1 per week via secure website. Modules included: information about burns and rehabilitation, psychological reactions after trauma, stress and sleep, family communication, relaxation strategies and exposure training. Homework assignment completed each week.	6 weeks
8. Wade, S. et al. (2005)	Internet-based family problem-solving intervention. 8 -12 sessions. Each session consisted of an on-line module (didactic content, video clips and exercises) followed by a video-conferencing session with a therapist. Modules completed by parents and children together.	No time range given.
9. Wade, S. et al. (2006)	Internet-based family problem-solving intervention plus training in cognitive behavioural skills relevant to coping with TBI. 8 -14 sessions. 8 core sessions including: problem-solving, communication and behaviour management. 6 sessions targeting stressors that may affect some families. Each session consisted of an on-line module followed by a video-conferencing session with a therapist. Modules completed by parents and children together. Participants spent between 0.5 to 3 hrs per week on the programme.	No time range given.
10. Wade, S. et al. (2008)	<p>Teen Online Problems Solving (TOPS) -10-16 sessions. 10 core sessions designed to promote executive functioning and social skills including: problem- solving, communication self-regulation, anger management and social skills training. 6 supplemental sessions to provide support for stressors/burdens of individual families including: caregiver stress, self-care, marital communication, working with the school, sibling concerns, pain management and talking with your adolescent.</p> <p>Each session consisted of an on-line module (didactic content, video clips and exercises) followed by a video-conferencing session with a therapist.</p> <p>Program directed towards teen but all family members encouraged to practice and implement the techniques. Participants encouraged to spend at least 1 hour a week accessing material. Parent and children could complete online modules simultaneously and independently.</p>	No time range given.
11. Wade, S. et al. (2012)	TOPS - as outlined in Wade et al. (2008) above. Only 4 supplemental sessions offered.	8 months.



## Support

All included studies provided additional support for participants from an intervention therapist/coach. Of the eleven studies: five included video-conferencing sessions (Studies 4, 8, 9, 10 and 11), two included video-conferencing sessions with 'bug-in-ear' technology (Studies 5 and 6), three provided individualised written feedback (Studies 1, 2 and 7), six provided initial face-to-face home visits sessions (Studies 4, 5, 8, 9, 10, and 11) and one provided brief messages via a message centre (Study 3).

For a large proportion of studies the purpose of support was to review the online material and provide support in implementing problem solving techniques (Studies 4, 5, 8, 9, 10, and 11). For others studies the purpose was to discuss the online content and receive live coaching via 'bug-in-ear' technology (Studies 5 and 6). One study aimed to provide of brief encouragement/support (Study 3) and others provided individualised written feedback in response to completed CBT homework assignments (Studies 1, 2 and 7). The purpose of initial face-to-face sessions (Studies 4, 5, 8, 9, 10, and 11) was to provide technical training for online intervention/technology usage and agree intervention goals. All eleven studies provided support to participants for the duration of the intervention. Most studies provided support either weekly or fortnightly (Studies 1, 2, 4, 5, 7, 8, 9 and 10). Two studies did not report information on the frequency of support (Studies 6 and 11) and one study provided brief support to participants whenever it was requested (Study 3). Only two studies reported estimated data on the total amount of support received (Studies 1 and 3) while other studies only reported support frequency; therefore, making it difficult to make direct comparison between studies. A variety of individuals provided support to participants in each study (See

Table 2). One study failed to provide information on the background of the supporter (Study 8). Nine of the eleven included studies reported that supporters received supervision to assess treatment fidelity (Studies 2, 3, 4, 5, 6, 9, 10 and 11).

### Randomisation

In nine of the eleven included studies participants were randomised into treatment condition groups. Six studies used a randomisation schedule created via computer programme (Studies 1, 3, 7, 9, 10 and 11), two used a random allocation sequence generator (Studies 5 and 6) and one did not include information regarding the method of randomisation (Study 4). Only one study used an independent researcher to complete the randomisation process (Study 1) and only one study reported that analysers were concealed to participant allocation (Study 6).

### Control Groups

A variety of control groups were used across studies (See Table 3) including: internet-based Information Resource Controls (IRC) (Studies 3, 4, 5, 6, 9 and 11), waiting list controls (Studies 1 and 7) and controls consisting of variations of the intervention - e.g. with audio added (Study 10). Two studies did not include any control groups (Studies 2 and 8).

**Table 2:** Support provided alongside internet-based interventions

<b>Authors (date)</b>	<b>Supporters</b>	<b>Modality</b>	<b>Content</b>	<b>Frequency/Duration</b>
1. Cernvall et al. (2015)	1 licensed Psychologist, 2 non-licensed Psychologists with Masters degrees.	Written feedback via on-line portal.	Written feedback provided in response to completed CBT homework assignments. Feedback was partially standardised.	Total of 15 -20 minutes support provided per week per participant.
2. Fidika, A. et al. (2015)	2 trained Psychotherapists.	No information.	Individualised feedback in response to each completed homework assignment, provided within 48 hours.	Weekly.
3. Palermo, T. et al (2016)	5 Study Coaches: 1 with Master's degree, 4 Ph.D. Psychology Fellows.	Message centre on web-based programme.	Participants could message study coach at any time during the treatment period. Standardised responses provided (from treatment manual) to every message received. Messages aimed at building rapport and encouraging skills practice.	Coaches spent no longer than 5 minutes responding to each message. Participants received on average an hour of coaching time.
4. Petranovich, C. et al. (2015)	4 Clinical Psychologists.	Face-to-face and video-conference (Skype) calls.	Initial face-to-face home visit session to identify intervention goals.  Video-conference calls to discuss on-line module and practice problem-solving techniques.	Initial home visit 90 mins duration. Weekly video-calls for the first 2-3 weeks then fortnightly video-calls between weeks 4–7.
5. Raj, S et al. (2015)	3 Clinicians with Master's degrees in Clinical Psychology.	Face-to-face and video-conference (Skype or Cisco Movi Client) calls.	Initial face-to-face home visit to meet participants and provide training for on-line content.  9 video-conference calls to discuss online module and practice parenting skills whilst receiving 'bug-	Initial home visit 90 mins duration. Weekly video-calls for the first 2-3 weeks then fortnightly video-calls

			in-ear' feedback.	between weeks 4–10.
6. Raj, S et al. (2018)	Clinicians with Master's degrees in Clinical Psychology.	Face-to-face and video-conference (Skype) calls.	As outlined in Raj et al. (2015) above.	No information.
7. Sveen, J. et al. (2017)	Psychologists or Psychotherapists.	Written feedback via internet-based platform.	Individualised feedback in response to each completed homework assignment.	Weekly.
8. Wade, S. et al. (2005)	Therapist	Video-conference calls.	Initial face-to-face home visit to meet participants, agree treatment goals and provide training for online content.  Video-conference calls to discuss completed on-line modules and practice problem-solving process with an identified goal.	Every 1 -2 weeks.
9. Wade, S. et al. (2006)	Clinical Psychology doctoral student	Video-conference calls.	As outlined in Wade et al. (2005) above.	Every 1 -2 weeks.
10. Wade, S. et al. (2008)	3 Licensed doctoral level Clinical Psychologists	Video-conference calls.	As outlined in Wade et al. (2005) above.	Every 1 to 2 weeks.
11. Wade, S. et al. (2012)	Staff Psychologist and doctoral students in Clinical Psychology.	Video-conference calls.	As outlined in Wade et al. (2005) above.	No information.

## Participants and Recruitment

Interventions trialled in the studies supported caregivers of children/adolescents with a range of chronic medical conditions. Over half of the studies (7/11) provided intervention for caregivers of children/adolescents with Traumatic Brain injury (TBI) (Studies 4, 5, 6, 8, 9, 10 and 11). Four further single studies provided support for carers of children/adolescents with cancer (Study 1), cystic fibrosis (Study 2), chronic pain (Study 3) and severe burns (Study 7). The majority of studies took place in the United States of America (USA) (Studies 4, 5, 6, 8, 9, 10 and 11). One study recruited participants from within the USA and Canada (Study 3), two studies took place in Sweden (Studies 1 and 7) and one in Germany (Study 2). All studies used convenience samples recruited from hospital/clinic attendees. The majority of carers recruited were female (range; 67% to 94.1%), however, 6 studies did not report information on carer gender. Carers ranged in mean age from 32.8 years to 41.9 years. Five studies did not report data on carer age. From the 11 studies 856 caregivers/families were enrolled in research to evaluate the potential efficacy of internet-based intervention in reducing caregiver stress. Over half of the studies has more than 27 participants randomised to each treatment condition (Studies 1, 2, 3, 4, 6 and 7).

## Outcome Measures

All studies used at least one standardised self-report measure to assess caregiver stress or quality of life. Nine of the studies measured self-report depressive symptoms (Studies 1, 2, 4, 5, 6, 8, 9, 10 and 11), three measured anxiety (Studies 1, 2 and 9), One measured post-traumatic disorder symptoms (Study 1), five studies utilized self-report measures of stress (Studies 5, 6, 7, 8 and 9) and seven

**Table 3:** Study Characteristics and Findings

Author (date), location, design	Participants: N, Population, Mean age (SD), Gender	Conditions	Outcome measures	Findings, effect sizes, attrition	Quality (CTAM)
1. Cernvall M. et al. (2015)  Sweden  RCT	N = 58 Caregivers of children receiving treatment for cancer who fulfilled the modified symptom criteria on the PCL-C.  Mean age = 38 (SD = 7.2). 39 (67% female).	Internet-based CBT self-help programme (n=31) Waiting list control group (n=27)	PCL-C  BDI-II BAI	Results indicated a significant effect of intervention on PTSD symptoms (PCL-C) with a large between-group effect size at post assessment (d = 0.88) and at 12 month follow up (d = 0.78). The intervention group reported significant reductions in depression (BDI-II) and anxiety (BAI) with large within-group effect sizes of d = 1.09 and 0.85, respectively (effect sizes reported from study article).  45% (N=14) in the intervention group and 26% (N=7) of the waiting-list group did not complete post assessment following intervention.	76/100
2. Fidika, A. et al. (2015)  Germany  Single group intervention study.	N = 31 Caregivers of children with Cystic Fibrosis (aged 0-17 yrs.) with clinically relevant symptoms of anxiety.  Mean age = 37 (SD = 6.2). 21 (91.3% female).	WEP-CARE-Online cognitive writing programme (n=31)  No Control group.	HADS CES-D PQoL	Participants reported significantly less symptoms of anxiety (HADS) at post-treatment and at 3 month follow-up with large within-group effect sizes of d = 2.06 and d = 1.36, respectively (all effect sizes reported from study article). Comparisons between pre and post-treatment resulted in lower symptoms of depression (CES-D) (within-group effect size d = 0.72) and higher quality of life (PQoL) (within-group effect size d = 0.76) - effect size reported from study article. These significant reductions were maintained at 3 month follow-up.  12.9% (N=4) of the intervention group did not complete the programme, a further 12.9% (N=4) did not complete post-treatment assessments and 9.7% (N=3) did not complete follow-up assessments.	43/100

3. Palermo, T. et al. (2016)  USA and Canada.  RCT	N = 273 adolescents (aged 11 to 17 yrs.) with chronic pain and their parents.  No caregiver age reported. 94.1% were female.	Internet-based CBT self-help programme (n = 138).  Internet delivered education control (n = 135).	BAPQ-PIQ	Exploratory analyses indicated benefits of internet CBT on caregivers. Participants in the intervention group in comparison to the education group reported significant reduction in anxiety symptoms on BAPQ-PIQ from baseline to 6 month follow-up (small to medium between-group effect size; $d = -0.39$ ). No significant differences in anxiety symptoms reported between conditions from baseline to post-treatment. Although not statistically significant, participants in the intervention group had a greater reduction in depressive symptoms (BAPQ-PIQ) in comparison to education control (between-group effect size $d = 0.27$ ). At 6 month follow-up, parents in the intervention group reported significantly greater reductions in depressive symptoms (BAPQ-PIQ) with a small to medium between-group effect size $d = 0.44$ . All effect sizes reported from study article.  5.07% (N=7) in the intervention group and 0.74% (N=1) of the education-control group did not complete post assessment following intervention. A further 0.72% (N=1) of the intervention group and 2.22% (N=3) of the education-control group did not complete follow-up assessments.	79/100
4. Petranovich, C. et al (2015)  USA  RCT	N = 132 families of adolescents with moderate to severe Traumatic Brain Injury (TBI).  Mean age of caregivers in intervention group =	Counsellor assisted problem-solving (CAPS) (n = 65).  Internet Information	GSI of the SCL-90-R.  CES-D	Lower income families who completed the intervention reported significantly lower global distress levels (GSI) in comparison to IRC condition at post-treatment, 12 and 18 months follow-up with small to moderate between-group effect sizes at $\beta = 0.45, 0.58$ and $0.71$ , respectively. All effect sizes reported from study article. No significant effect of condition on depression scores (CES-D). 6.1% (N=4) in the intervention group and 4.4% (N=3) of	79/100

	41.9 (SD = 7.34). 92.3% were female.	Resource Control (IRC) (n = 67).		the information-control group did not complete post assessment following intervention. 14.7% (N=13) of the intervention group and 4.6% (N=6) of participants did not complete follow-up assessments at 12 months and 13.4% (N=20) of the intervention group and 11.4% (N=13) of the information-control group did complete follow-up assessments at 18 months.	
5. Raj, S. et al. (2015)  USA  RCT	N = 37 caregivers of children (aged 3-9 yrs.) with a moderate to severe TBI.  Mean age of caregivers in intervention group = 32.8 (SD = 7.36). No gender information reported.	I-InTERACT On-line programme (n = 20)  IRC (n = 20).	GSI of the SCL-90-R.  CES-D  PSI	Family income significantly moderated treatment effects on caregiver functioning. Parents with lower income reported significant reductions in global psychological distress (GSI) from baseline to follow-up.  No significant group differences in depressive (CES-D) symptoms or parenting stress (PSI) between parents in I-InTERACT and IRC.  15% (N=3) in the intervention group and 5% (N=1) of the IRC group did not complete assessments post- intervention.	74/100
6. Raj, S. et al. (2018)  USA  RCT	N = 148 caregivers of 117 children (aged 3- 9 yrs.) with a moderate to severe TBI.  Mean caregiver age and gender data not reported.	I-InTERACT On-line programme (n = 41)  I-InTERACT Express On-line programme (n = 37)  IRC (n = 39).	GSI of the SCL-90-R CES-D  PSI  CSES	Analyses revealed no main effects of treatment on caregiver stress (GSI), parenting stress (PSI) or parenting efficacy (CSES) at post-treatment. Participants in the I-InTERACT group experienced reductions in depression symptoms (CES-D) in comparison to the control group when baseline severity was considered as a moderator.  21.9% (N=9) in the I-InTERACT intervention group, 21.6 % (N=8) of the I-InTERACT Express group and 12.8% (N=5) of the IRC group did not complete assessments post-intervention (3 months). 19.5% (N=8) in the I-InTERACT intervention group,	79/100



				24.3 % (N=9) of the I-InTERACT Express group and 15.4% (N=6) of the IRC group did not complete assessments at 6 month follow-up. No significant differences were no significant differences in caregiver completion rates of follow up assessments across the three groups.	
7. Sveen, J. et al. (2017)  Sweden  RCT	N = 62 caregivers of children with severe burns under the age of 18 yrs.  Mean age of intervention group = 36.4 (SD =6.6). 42 (67.7% female).	Internet-based self-help programme (n = 31)  Waiting list control (n = 31)	IES-R  PSI  PSS	Analyses indicated a significant effect of intervention on parents self-reported IES-R scores with participants in the intervention group reporting lower scores at post-assessment than those in the control group (with a medium between-group effect size d = 0.62 – calculated from data reported in study article for the purpose of the systematic review).  There was no significant interaction effect on participant PSS or PSI.  32.26% (N=10) of the intervention group and 3.22% (N=1) of control group dropped out of the study. 25.8% (N=8) 6.45% (N=2) and 19.35% (N=6) of the intervention group did not complete assessments at post-treatment, 3 months follow-up and 6 months follow-up respectively. 9.67% (N=3) 3.22% (N=1) and 6.45% (N=2) of the control group did no complete assessments at post-treatment, 3 months follow-up and 6 months follow-up respectively.	69/100
8. Wade, S. et al. (2005)  USA	N = 19 participants including; children with moderate to severe TBI (n = 6), their parents (n = 8)	Internet-based family problem-solving intervention	GSI of the SCL-90-R.  CES-D	Participants reported significant differences from baseline to follow-up in parenting stress (PSI), depression (CES-D), and global psychological symptoms (GSI).	30/100

Single group intervention study.	and siblings (n = 5).  Mean caregiver age and gender data not reported.	(n = 19)  No control condition.	PSI	No data on attrition reported.	
9. Wade, S. et al. (2006)  USA  RCT	N = 46 families of children with moderate to severe TBI.  Mean caregiver age and gender data not reported.	On-line family problem solving therapy website (n = 26).  IRC (n = 20).	GSI of the SCL-90-R.  CES-D  AI  PSI	Parents in the intervention group reported significantly less global distress(GSI), depressive symptoms (CES-D) and anxiety (AI) than the IRC group with moderate to large between-group partial eta <sup>2</sup> effect sizes of $\eta^2 = 0.16, 0.16$ and $0.11$ , respectively. All effect sizes reported from study article.  No significant differences in parenting stress (PSI) were reported.  19.23% (N=5) of the intervention group and 0% of the IRC group did not complete assessments at post-treatment.	67/100
10. Wade, S. et al. (2008)  USA  Randomised Trial	N = 9 families of adolescents with moderate to severe TBI.  Mean caregiver age and gender data not reported.	Teen Online Problem Solving (TOPS) with audio (n=5).  TOPS without audio (n=4).  No control condition.	GSI of the SCL-90-R.  CES-D	Parental ratings of depressive symptoms (CES-D) declined significantly from baseline to follow-up with a within-group effect size of $d = 0.80$ . Effect size reported from study article. No significant effects of intervention were found for parental global distress (GSI).  0% attrition rate - all participants completed all 10 core sessions.	47/100

11. Wade, S. et al. (2012) USA  RCT	N = 41 families of adolescents (aged 11- 18 yrs.) with moderate to severe TBI.  Mean age of caregivers in intervention group = 40.81 (SD = 4.49). Gender data not reported.	TOPS (n = 21)  IRC (n = 20)	GSI of the SCL-90-R.  CES-D  SPSI-R: S	Parents of lower socio-economic status in the intervention group reported significant reductions in depressive symptoms (CES-D) from baseline to follow- up with a moderate between-group effect size ( $\beta$ .=0.59). Effect size reported from study article.  Significant improvements were reported by those in the intervention group for both positive problem orientation and rational problem-solving (SPSI-R: S).  23.8% (N=5) of the TOPS group and 5.26% (N=1) of the IRC group did not complete assessments at post- treatment.	74/100
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Abbreviations: AI, The Anxiety Inventory; BAI, Beck Anxiety Inventory; BAPQ-PIQ, The Bath Adolescent Pain Questionnaire- Parent Impact Questionnaire; BDI-II, Beck Depression Inventory-II; CES-D, The Centre for Epidemiological Studies Depression Scale; CSES, The Caregiver Self-Efficacy Scale; GSI, The Global Severity Index; HADS, Hospital Anxiety and Depression Scale; IES-R, The Impact of Event Scale-Revised; PCL-C, The PTSD Checklist Civilian version; PQoL, The ULM Quality of Life Inventory for Parents of Chronically ill children; PSI, The Parenting Stress Index 3<sup>rd</sup> edition – short form; PSS, The Perceived Stress Scale; SCL-90-R, The Symptom Checklist-90-revised; SPSI-R: S, The Social Problem-solving Inventory- Revised Short form.

measured carer global psychological distress (Studies 4, 5, 6, 8, 9, 10 and 11). Only one study measured caregiver quality of life (Study 2). Only one study (Study 1) required caregivers to present with clinical significant mental health difficulties at baseline.

## Quality

The mean CTAM scores from the 11 included studies was 65.2 (SD= 17.1, range 30-79). Eight out of the eleven studies met the cut off of  $\geq 65$  (Tarrier and Wykes, 2004) and were deemed to be of an acceptable quality.

## Analysis

All statistical analyses were appropriate for study design and outcomes reported. Various statistical approaches were used and effect sizes were reported in a proportion to the paper. When data was available, effect sizes were calculated (if not already reported within the study). Only three of the studies reported utilising an intention-to-treat analysis (Studies 1, 7 and 9).

## Findings

Of the single interventions studies, all (Studies 2, 8 and 10) reported significant treatment effects for measures of caregiver stress, including: large within-group effect sizes for anxiety (Study 2) and depression (Study 10) and moderate within-group effect sizes for depression and quality of life (Study 2). One study (Study 10) reported no significant treatment effects on measures of parental global distress.

Of the RCTs, all (Studies 1, 3, 4, 5, 6, 7, 9 and 11) reported significant treatment effects on at least one measure of caregiver stress. Large between-group effect sizes were reported for PTSD (Study 1), Depression (Studies 1 and 9) and global distress (Study 9). Moderate between-group effect sizes were reported for depression (Study 11), anxiety (Study 9) and impact of events (Study 7). Small effect sizes were noted in study 3 for reductions in anxiety and in study 4 for global distress. Study 5 reported significant reductions in caregiver global distress, although published data did not allow between-group effect sizes to be calculated.

Results from studies were, however, varied with some reporting no significant effect of internet interventions on depression (Study 4, 5 and 6) or caregiver stress (Studies 5, 6 and 7).

#### Treatment Efficacy and Durability

Only four studies reported follow-up data on treatment effect durability. Of the single intervention studies - Study 2 reported maintained treatment effects for caregiver stress at follow-up on measures of depression, quality of life and anxiety. Of the RCTs, Study 1 reported a large between-group effect size for the intervention in reducing PTSD symptoms at 12 month follow-up. Study 3 reported small to medium between-group effect sizes for the intervention in reducing anxiety and depression at 6 month follow-up and Study 4 demonstrated maintained treatment effects with medium between-group effect sizes for global distress at 12 and 18 months post-intervention.

## DISCUSSION

This systematic review identified a range of internet-based interventions targeted towards caregivers of children with a variety of chronic conditions. Therapeutic approaches utilised within interventions (e.g. family problem-solving and CBT) have been shown to have beneficial effects on patient and caregiver well-being in other studies (Barlow et al. 2004; Law et al. 2014). The internet-based interventions reviewed included elements such as: self-management, communication tools, feedback, information and education. These are similar to features which have been utilised and reported to be beneficial in internet-based interventions for patients with chronic conditions (Kuijpers et al. 2013; Stinson et al. 2008). Results from this review did not, however, indicate any clear factors (e.g. treatment approach, duration, type of support) to suggest what intervention approach may be most effective.

All studies reported significant treatment effects on at least one measure of caregiver well-being/stress with studies reporting treatment effects which ranged from small to large. These results are in line with other reviews of technology-based interventions for caregivers (Powell et al. 2008). A number of outcome measures were used to assess caregiver stress, therefore, making direct comparison of efficacy between the included studies challenging. Eight out of eleven of these studies were deemed to be of acceptable quality with those that did not being of earlier publication dates.

All of the Interventions in the included studies used some form of support for participants from an intervention coach/therapist, either to provide feedback/encouragement, training or as an active element of treatment. Previous

research has suggested that guidance/support in addition to internet-interventions can be influential in promoting adherence (Zarski et al. 2016). However, other research has indicated that additional support does not necessarily produce any further benefits than internet-based intervention alone in symptom reduction (Farrer et al. 2011). Further investigation is required to establish the role of support in internet-based intervention acceptability and efficacy.

This review has several limitations. Studies used a variety of therapeutic approaches within the internet-based interventions and recruited participants from different countries with different health care systems. This made direct comparison of the interventions challenging. The scope of this review also did not report data on participant satisfaction, intervention acceptability and attrition. Further qualitative data is required on the experience of users and the uptake of internet-based interventions to establish if the internet is a useful way of delivering supports for caregivers.

Further research may benefit from investigating different uses of internet technology to promote patient care including: the use of discussion forums to connect caregivers to peer-support, promoting communication with health professionals, links to internet-based information resources and group video conferencing. Other research may wish to explore whether interventions should target both children/adolescents and caregivers or solely caregivers and if differences in target audience impact upon treatment efficacy in reducing caregiver stress. Five studies included in this review had a target audience of caregivers, with the remaining six studies providing interventions for both children/adolescents and their caregivers. Research has suggested that when patients present with higher rating of quality of life, caregivers also report higher

levels too (Shahi et al. 2014), suggesting that it may be beneficial for internet-interventions to target both patients and caregivers - further exploration of this effect is required for internet-based interventions.

To assist in comparability of studies, future research would benefit from incorporating more widely used measures of caregiver-wellbeing to allow direct comparisons to be made. It is also evident that few trials have been conducted exploring the potential efficacy of internet-based interventions for caregivers. More high-quality randomised controlled trials with treatment-as-usual controls would help to establish if the internet-based interventions are beneficial to caregivers in reducing caregiver stress.

## **CONCLUSION**

This review suggests that internet-based interventions were mostly effective in reducing elements of caregiver stress. The review highlights the need for further high quality trials offering internet-based interventions to caregivers of children/adolescents with chronic medical conditions to assess their true potential effectiveness, explore different technological delivery methods and investigate their acceptability to caregivers.



## REFERENCES

Barlow, J.H. and Ellard, D.R., 2004. Psycho-educational interventions for children with chronic disease, parents and siblings: An overview of the research evidence base. *Child: care, health and development*, 30(6), pp.637-645.

Cernvall, M., Carlbring, P., Ljungman, L., Ljungman, G. and von Essen, L., 2015. Internet-based guided self-help for parents of children on cancer treatment: a randomized controlled trial. *Psycho-Oncology*, 24(9), pp.1152-1158.

Cernvall, M., Carlbring, P., Wikman, A., Ljungman, L., Ljungman, G. and von Essen, L., 2017. Twelve-month follow-up of a randomized controlled trial of internet-based guided self-help for parents of children on cancer treatment. *Journal of medical Internet research*, 19(7), pp.1-12.

Cousino, M.K. and Hazen, R.A., 2013. Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, 38(8), pp.809-828.

Dyer, E.A., Kansagara, D., McInnes, D.K., Freeman, M. and Woods, S., 2012. Mobile applications and Internet-based approaches for supporting non-professional caregivers: a systematic review. *QUERI, Department of Veterans Affairs Health Services Research and Development Service, Washington, DC*.

Eccleston, C., Fisher, E., Law, E., Bartlett, J. and Palermo, T.M., 2015. Psychological interventions for parents of children and adolescents with chronic illness. *The Cochrane database of systematic reviews*, 4, pp.CD009660.

- Eccleston, C., Palermo, T.M., Fisher, E. and Law, E., 2012. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane database of systematic reviews (Online)*, 8, pp.CD009660.
- Farrer, L., Christensen, H., Griffiths, K.M. and Mackinnon, A., 2011. Internet-based CBT for depression with and without telephone tracking in a national helpline: randomised controlled trial. *PloS one*, 6(11), pp.e28099.
- Fidika, A., Herle, M., Lehmann, C., Weiss, C., Knaevelsrud, C. and Goldbeck, L., 2015. A web-based psychological support program for caregivers of children with cystic fibrosis: a pilot study. *Health and quality of life outcomes*, 13(1), pp.11.
- Hu, C., Kung, S., Rummans, T.A., Clark, M.M. and Lapid, M.I., 2014. Reducing caregiver stress with internet-based interventions: a systematic review of open-label and randomized controlled trials. *Journal of the American Medical Informatics Association*, 22(e1), pp.e194-e209.
- Keeley, B. and Clarke, M., 2002. Carers Speak Out Project. *Report on findings and recommendations. London: Princess Royal Trust for Carers.*
- Kuijpers, W., Groen, W.G., Aaronson, N.K. and van Harten, W.H., 2013. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. *Journal of medical Internet research*, 15(2).
- Law, E.F., Fisher, E., Fales, J., Noel, M. and Eccleston, C., 2014. Systematic review and meta-analysis of parent and family-based interventions for children and adolescents with chronic medical conditions. *Journal of Pediatric Psychology*, 39(8), pp.866-886.

Moher, D., Liberati, A., Tetzlaff, J. and Altman, D.G., 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, 151(4), pp.264-269.

NHS Health and Social Care Information Centre, 2010. *Survey of carers in households in England 2009–10*. Leeds, England. Available at: <http://www.hscic.gov.uk/pubs/carersurvey0910> [Accessed on 3 April 2018].

NICE, 2009. Depression in adults: recognition and management (CG90) [pdf] Available at: <https://www.nice.org.uk/guidance/cg90/resources/depression-in-adults-recognition-and-management-pdf-975742636741> [Accessed 3 June 2018].

NICE, 2011. Generalised anxiety disorder and panic disorder in adults: management (CG113) [pdf] Available at: <https://www.nice.org.uk/guidance/cg113/resources/generalised-anxiety-disorder-and-panic-disorder-in-adults-management-pdf-35109387756997> [Accessed 3 June 2018].

Office for National Statistics. Social Survey Division. (2006). General Household Survey, 2000-2001. [data collection]. *3rd Edition*. UK Data Service. Available at: <http://doi.org/10.5255/UKDA-SN-4518-1> [Accessed on 3 June 2018].

Palermo, T.M., Law, E.F., Fales, J., Bromberg, M.H., Jessen-Fiddick, T. and Tai, G., 2016. Internet-delivered cognitive-behavioral treatment for adolescents with chronic pain and their parents: A randomized controlled multicenter trial. *Pain*, 157(1), pp.174.

Petranovich, C.L., Wade, S.L., Taylor, H.G., Cassedy, A., Stancin, T., Kirkwood, M.W. and Maines Brown, T., 2015. Long-term caregiver mental health outcomes following a predominately online intervention for adolescents with complicated mild

to severe traumatic brain injury. *Journal of pediatric psychology*, 40(7), pp.680-688.

Powell, J., Chiu, T. and Eysenbach, G., 2008. A systematic review of networked technologies supporting carers of people with dementia. *Journal of telemedicine and telecare*, 14(3), pp.154-156.

Raj, S.P., Antonini, T.N., Oberjohn, K.S., Cassedy, A., Makoroff, K.L. and Wade, S.L., 2015. Web-based Parenting Skills Program for Pediatric Traumatic Brain Injury Reduces Psychological Distress Among Lower-income Parents. *Journal of Head Trauma Rehabilitation*, 30(5), pp.347-356.

Raj, S.P., Shultz, E.L., Zang, H., Zhang, N., Kirkwood, M.W., Taylor, H.G., Stancin, T., Yeates, K.O. and Wade, S.L., 2018. Effects of Web-Based Parent Training on Caregiver Functioning Following Pediatric Traumatic Brain Injury: A Randomized Control Trial. *The Journal of head trauma rehabilitation*.

Shahi, V., Lapid, M.I., Kung, S., Atherton, P.J., Sloan, J.A., Clark, M.M. and Rummans, T.A., 2014. Do age and quality of life of patients with cancer influence quality of life of the caregiver? *Journal of geriatric oncology*, 5(3), pp.331-336.

Stinson, J., Wilson, R., Gill, N., Yamada, J. and Holt, J., 2008. A systematic review of internet-based self-management interventions for youth with health conditions. *Journal of pediatric psychology*, 34(5), pp.495-510.

Sveen, J., Andersson, G., Buhrman, B., Sjöberg, F. and Willebrand, M., 2017. Internet-based information and support program for parents of children with burns: a randomized controlled trial. *Burns*, 43(3), pp.583-591.

Tarrier, N. and Wykes, T., 2004. Is there evidence that cognitive behaviour therapy is an effective treatment for schizophrenia? A cautious or cautionary tale?. *Behaviour Research and Therapy*, 42(12), pp.1377-1401.

Wade, S.L., Carey, J. and Wolfe, C.R., 2006. An online family intervention to reduce parental distress following pediatric brain injury. *Journal of Consulting and Clinical Psychology*, 74(3), pp.445.

Wade, S.L., Walz, N.C., Carey, J., McMullen, K.M., Cass, J., Mark, E. and Yeates, K.O., 2012. A randomized trial of teen online problem solving: Efficacy in improving caregiver outcomes after brain injury. *Health psychology*, 31(6), pp.767.

Wade, S.L., Walz, N.C., Carey, J.C. and Williams, K.M., 2008. Preliminary efficacy of a Web-based family problem-solving treatment program for adolescents with traumatic brain injury. *The Journal of head trauma rehabilitation*, 23(6), pp.369-377.

Wade, S.L., Wolfe, C., Brown, T.M. and Pestian, J.P., 2005. Putting the pieces together: Preliminary efficacy of a web-based family intervention for children with traumatic brain injury. *Journal of Pediatric Psychology*, 30(5), pp.437-442.

Zarski, A.C., Lehr, D., Berking, M., Riper, H., Cuijpers, P. and Ebert, D.D., 2016. Adherence to internet-based mobile-supported stress management: a pooled analysis of individual participant data from three randomized controlled trials. *Journal of medical Internet research*, 18(6).

## **Chapter 2: Major Research Project**

### **An Online CBT-based Life Skills Course for Carers of Children with Chronic and Life Limiting Conditions: a Feasibility Trial**

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## PLAIN ENGLISH SUMMARY

**Title:** An Online CBT-based Life Skills Course for Carers of Children with Chronic and Life Limiting Conditions: a Feasibility Trial

**Background:** Caring for a child with a chronic health condition is often associated with high levels of anxiety, depression and stress (Burton et al., 2003). Demanding caring duties, a lack of time and social isolation often means carers struggle to seek help (Acton, 2002). The internet may be useful way to offer carers psychological supports, however, to date no research has explored this.

**Aims:** This study aimed to investigate common difficulties carers face, adapt a computerised cognitive behavioural therapy course to suit their needs and examine how possible it is to deliver it to carers.

**Methods:** Hospice staff at a single hospice in Glasgow were recruited through flyers and emails to participate in a focus group and a complete questionnaire exploring their thoughts on common difficulties carers face. A widely used online CBT-based course was then modified based on these comments to provide content aimed at supporting carers. Carers of children with chronic illness were then recruited to a feasibility trial of the revised course through online adverts, flyers and recommendation by local hospice staff over a 7 month period. Carers received weekly support via email for six weeks. Carers completed questionnaires measuring anxiety, low mood and everyday functioning at the beginning and end of the course.

**Results:** 19 Hospice staff completed the questionnaire about carer difficulties. Several topics were identified which were used to adapt the online course. 29 carers were recruited to trial the new online course (LLTTF for Carers of Children

and Young People Facing Illness). Advertisements on social media were the most successful method of recruitment. 12 (41.4%) of the carers recruited logged onto the course, 11 (37.9%) used at least one element of the online course and 6 (20.7%) completed questionnaires in the final evaluation at 6 weeks. Overall only 2 (6.9%) carers completed all of the 6 course modules suggested by the researchers. There was no significant changes in depression, everyday functioning or anxiety but results did show a slight reduction in anxiety and functional impairment measured by the Work and Social Adjustment Scale (WSAS, Mundt et al., 2002). Questionnaires completed by carers at the end of the online course indicated a high level of satisfaction with the course. Qualitative results showed that participants valued the email support they received and the flexibility that the online approach provided. However, some carers still struggled to find time to complete the course.

**Conclusion:** Computerised courses may be an acceptable way of offering mental health support to some carers. Difficulties in retention, recruiting and engaging carers suggest that further adaptations to the course are needed to improve engagement (e.g. moving to shorter stand-alone modules rather than delivery as a recommended course, and delivery using an app format). Alternative methods of delivering psychological support should be explored to avoid excluding those who do not have access to the internet.

### **Key References:**

Acton, G. J., 2002. Health-promoting self-care in family caregivers. *Western Journal of Nursing Research*, 24(1), pp.73-86.



Burton, L.C., Zdaniuk, B., Schulz, R., Jackson, S. and Hirsch, C., 2003. Transitions in spousal caregiving. *The Gerontologist*, 43(2), pp.230-241.

Mundt, J.C., Marks, I.M., Shear, M.K. and Greist, J.M., 2002. The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry*, 180(5), pp.461-464.

## SCIENTIFIC ABSTRACT

**Background:** Caring for a child with a chronic health condition is often associated with high levels of anxiety, depression and stress (Burton et al., 2003). Demanding caring duties, a lack of time and social isolation create barriers for carers accessing mental health support. The internet may be useful way for carers to access psychological supports but to date no research has explored this.

**Aims:** To identify common difficulties which carers face and adapt a pre-existing computerised CBT (cCBT) based course to reduce carer stress. To determine the feasibility of providing mental health support to carers through an online course and assess its potential effectiveness and accessibility.

**Methods:** Focus groups and questionnaires completed by hospice staff provided information regarding common stressors encountered by carers. Thematic analysis (Braun and Clarke, 2006) was used to identify topics which were then used to adapt a pre-existing cCBT course which consisted of 6 primary modules and additional online materials/modules plus the offer of weekly email support for 6 weeks from a support worker to encourage use. A single arm feasibility trial of the tailored cCBT was conducted using carers of children with chronic conditions recruited through advertisements and local hospice staff. Participants were provided with access to the cCBT course for 6 weeks and received weekly personalised support emails. Self-report measures of anxiety, depression and daily functioning were measures at baseline and at post-treatment. Questionnaires administered online explored participant satisfaction and course use which were then analysed.

**Results:** 19 hospice workers were recruited to complete questionnaires regarding common difficulties faced by carers. Several themes emerged from thematic analysis of the data including: physical and interpersonal difficulties, external pressures, time constraints, limited support, responding to the child's illness and difficulties accessing appropriate care for their child.

29 carers were recruited to trial the online course, with 55.6% recruited through social media. 12 (30.8%) carers logged onto the course and 6 (15.4%) completed follow-up measures at 8 weeks post intervention. Of the participants that started the course only 2 (18.2%) completed all 6 course modules. Exploratory analyses showed no statistically significant differences in depression, anxiety or functional impairment. However, results indicated a general reduction in clinically significant anxiety symptoms and functional impairment. Satisfaction questionnaires completed by carers post-intervention indicated a high level of satisfaction with the course. Qualitative results showed that participants valued the email support they received and the flexibility that an online approach provided. Some carers still struggled to find time to complete the course and suggestions were made to amend the course to enable it to be accessed offline and on portable devices.

**Conclusion:** Computerised courses may be an acceptable way of offering mental health support to some carers. Difficulties in retention and recruiting suggest that further adaptations to the course are needed to improve engagement (i.e. delivering the course via apps, or moving to stand alone course topics rather than a recommended course). Alternative methods of delivering psychological support should be explored to avoid excluding those who do not have internet access.

**Keywords:** Internet, intervention, CBT, caregivers, children, chronic.

## INTRODUCTION

Over the last century, vast improvements in paediatric care have led to children with life threatening and chronic conditions surviving longer, some even into adulthood (Nelson, Hexem & Feudtner, 2012). Depending on the definition used, it is estimated that between 13 and 27% of all children are affected by chronic conditions (Van Cleave, Gortmaker & Perrin, 2010) with some of the most common being epilepsy, asthma, diabetes and arthritis.

Approximately 6.8 million adults in Britain currently provide care to individuals with physical/mental health conditions (Office for National Statistics, 2006) with recent trends suggesting that individuals are more likely to be involved in longer periods of caring (Hirst and Hutton, 2000). It is estimated that 8% of carers look after disabled children under the age of 18 and another 5% care for young people over the age of 18 (NHS Information Centre for Health and Social Care, 2010).

The NHS and social services rely heavily on family/friends' willingness and ability to provide unpaid care. Research has estimated the value of this care to be worth approximately £119bn per year - more than the total annual spend of NHS England (Carers UK & the University of Leeds, 2011).

Unfortunately, caring for a child with a chronic condition can significantly affect the wellbeing of the carer as well as the young person (Eccleston, Palermo, Fisher & Law, 2012). Carers can face a number of challenges in supporting their child and managing their care (Lewis and Prescott, 2006). Stressors including: frequent hospitalizations, difficulties in accepting a child's diagnosis, increased strain on the parenting role, child functional impairments and difficulties liaising with medical staff - all contribute towards increased levels of emotional distress amongst carers

(Barlow & Ellard, 2006; Cousino & Hazen, 2013). Caregivers have also been found to report higher levels of parenting distress compared to caregivers of healthy children (Cousino & Hazen, 2013).

Literature indicates that caring can have an adverse impact on carers' physical and emotional wellbeing including general health problems, social isolation, physical injuries (e.g. as a result of lifting), marital distress and poor mental health (Parker, 1993; Warner, 1995; Arksey *et al.*, 2000; Keeley & Clarke, 2002; Dahlquist *et al.*, 1993, Cadman, Rosenbaum, Boyle & Offord, 1991). A breadth of research has identified an association between caregiving and increased rates of anxiety and depression (Burton *et al.*, 2003; Schultz *et al.*, 1990; Schultz *et al.*, 1995). Nearly 40% of carers taking part in the General Household Survey for 2000 reported that their physical or mental health had been affected as a result of caring (Maher and Green, 2002). An alarming 84% of carers in a recent survey reported that they had experienced depression and 77% reported feeling more anxious because of their caring role (Carers UK, 2015).

A recent review of psychological interventions for carers of young people with chronic illness found that Problem-solving based therapy had a beneficial effect on parental behaviour and parental mental health post-treatment (Eccleston *et al.* 2015). Support for carers can also be obtained from medical staff and community resources, with carers reporting great benefits from hospice support (Davies *et al.* 2004). This evidence suggests that psychological supports may be of some benefit in reducing carer distress and rates of burnout.

Unfortunately, barriers including; higher levels of isolation (Contact a Family, 2011; Becker, 2000; Howard, 2001), limited practical and financial support (Carers UK,

2012), geographic limitations and limited time (Keeley and Clarke, 2002) prevent carers from accessing these types of support when they are offered. This leaves carers vulnerable to being excluded from accessing services. Astonishingly, it has been found that the more demanding the caring role, the less likely carers are to seek support for their own health (Acton, 2002). This, in addition to other situational factors, leaves carers at heightened risk of developing mental health difficulties.

One way of overcoming barriers to accessing mental health supports is to investigate alternative methods of delivery for psychological support. Research has highlighted the potential value of specific packages targeted at improving carer wellbeing. In some chronic disorders (e.g. anorexia), specific packages for parents have shown to improve carer mood, reduce anxiety, build confidence and reduce expressed emotion. Alternative trialled methods of delivering psychological support for carers include: online packages (Grover et al., 2011), DVD audio-visual programmes (Sepulveda et al, 2008) and book-based treatments (McCann et al. 2012).

In wider mental health services, computerised Cognitive Behavioural Therapy (cCBT) is a recommended treatment option for depression and anxiety disorders (NICE, 2009, 2011). This methods of treatment provides a reliable structure for delivery, greater capacity for support and a more flexible approach of delivery which would be essential for carers with limited time.

A scoping review has identified limited research evaluating psychological interventions for carers of young people with chronic conditions. Given the evidence base for cCBT and its potential to overcome barriers to treatment

accessibility, this study aims to assess the feasibility of a cCBT skills based course for carers.

### **Study 1: Qualitative Staff Survey**

#### **AIMS**

1. Explore common stressors that carers face in relation to caring for a young person with a chronic condition.
2. Gather sufficient qualitative data to meet saturation of data.
3. Analyse data to generate themes of stressors/difficulties which are descriptive of common stressors faced by carers.
4. Use gathered data to tailor the content of a pre-existing cCBT course to suit the needs of carers.

#### **METHODS**

##### **Participants**

Participants included multi-disciplinary hospice and community staff based at Robin House Children's Hospice in the west of Scotland.

##### **Recruitment**

Meetings were held between the primary researcher and senior staff at Robin House to discuss the research purpose and aims before recruitment began. Participants for the staff survey were mainly recruited through word of mouth at team meetings and via emails sent by senior hospice staff and flyers.

## **Consent**

Information sheets regarding the research were provided to participants in advance and at the time of survey completion. After reading the information sheet participants were invited to provide informed consent by completing a paper consent form.

## **Procedures**

After informed consent was obtained, participants attended a 30 minute presentation by the primary researchers. This included a verbal introduction accompanied by a PowerPoint presentation on the pre-existing online course “Living Life to the Full” (LLTTF). Concepts of how it could be adapted to suit carer needs were also discussed and an overview of the research provided. Participants were then invited to participate in a 30 minute focus group which was led by the primary researcher using a semi-structured interview schedule (Appendix 3.11). The focus group session was recorded on a digital voice recorder. Staff were invited to share comments about the online course, opinions about content and thoughts on how it could be adapted. Following the focus group, staff were asked to complete a brief questionnaire (See Appendix 3.12) to gather data regarding common stressors carers face. This data was later used to adapt the pre-existing cCBT course.

## **Data analysis**

Transcribed data from the focus group recordings and written responses from the questionnaires were analysed qualitatively using thematic



analysis. The analysis was conducted following Braun and Clarke (2006) six phase Open Coding Process: 1. Familiarising yourself with the data, 2. Generating initial codes, 3. Searching for themes, 4. reviewing themes, 5. Defining and naming themes, 6. Producing the report. A semantic theoretical approach was adopted when completing the thematic analysis in that codes and their development reflected the explicit content of the data. Data was managed and coded by hand. Initial themes were identified by the primary researcher and discussed and confirmed with a colleague (CB). Thematic analysis was selected as an appropriate method for qualitative analysis due to its emphasis on examining and identifying 'themes' within the data. As an approach, it is highly inductive in that themes emerge from gathered data rather than being imposed on by the researcher. Thematic analysis was therefore identified as an appropriate approach for data analysis. The aim of the analysis was to identify useful topics to include in the online course for carers.

## **RESULTS**

### **Sample characteristics**

19 staff members from Robin House Children's Hospice were recruited to complete a brief questionnaire and participate in a focus group regarding the development of cCBT course for carers. Of the 19 participants, 17 (89.5%) were female and 2 (10.5%) were male. The average age of participants was 44 years (SD = 7.8) with an average of 9.4 (SD = 4.3) years' experience working with carers of children with chronic conditions. Participants came from a variety of

professional backgrounds (See Table 1). All but one of the participants stated that they provided both emotional and practical support to carers. 21.1% reported that they had received formal training in mental health in addition to their professional training.

### Quantitative results

Using a 6 point 'Likert' type scale (with 6 being the most confident and 1 being the least) participants reported a mean confidence rating of 4.4 (SD = 1.2) when speaking to carers about emotional difficulties and a mean confidence rating of 4.8 (SD = 1.1) when discussing practical difficulties.

**Table 1:** Participant Professional Background

Professional Background	N	%
Doctor	2	10.6
Nurse	8	42.4
Support Worker	2	10.6
Social Worker	1	5.3
Chaplain	1	5.3
Physiotherapist	1	5.3
Early Years Worker	3	15.9
Other	1	5.3

### Qualitative Results

Participants were asked a number of open ended questions via questionnaire. These regarded their experiences of what sources of support carers found beneficial, practical problems that carers face and topics which carers find difficult

to discuss with others. Themes were identified for each question using thematic analysis. These were cross checked with a colleague (CB).

- **Common difficulties and stressors that carers face**

Participants identified a number of difficulties that carers of children with chronic and life-limiting conditions face.

Seven main themes were identified as follows.

1. Physical implications of the caring role

Participants reported that many carers struggle with the physical demands of caring including: *“Moving and lifting”* (Participant [P] 2) and *“sore backs”* (P1). They also commented on the impact of *“sleep deprivation”* (P15) referring to carers’ difficulties in *“trying to cope with decreased sleep”* (P6), and *“tiredness”* (P18).

2. Implications of caring role on interpersonal relationships

Participants highlighted a general theme of carers having difficulties with maintaining balanced relationships within the family: having a *“lack of time to spend with other siblings”* (P10, P19), *“Fear that they are not giving their other children enough time/attention”* (P9), *“Being all things to all people i.e. roles, expectations, worries about not being there for everyone or not doing a ‘good enough’ job”* and *“relationship difficulties”* (P17).

3. External pressures exacerbated by the child’s needs

Participants repeatedly mentioned the impact of external factors on carer wellbeing. Frequently mentioned factors included financial hardship (*“financial*

*difficulties*” [P3,P7], *Money issues*” [P11]), lack of adapted and accessible housing for their child’s needs (*“housing problems”* [P11], *“Lack of equipment/facilities”* [P12] and poor *“housing adaptations”* [P14]) and difficulties with transport (*“getting children to school/appointments”* [P11], *“going out and about”* [P14] and *“transport issues”* [P18]).

#### 4. Time constraints

Participants commented on the challenges carers face in managing time and multiple caring demands efficiently; (*“Increase in care hours”* [P6], *“time to do all the things they need”* [P9], *“multiple demands”* [P6], *“multiple hospital appointments”* [P15] and *“time constraints”* [P5]).

#### 5. Limited support for carers

Carers were reported to encounter significant difficulties with finding adequate supports. This included a lack of support systems (*“lack of support from family/staff”* [P11], *“isolation”* [P9], *“single parent family”* [P16]), Limited self-care (*“No down time”* [P5], *“Having no time for themselves”* [P5]) and a lack of understanding/emotional support for carers (*“unable to share feelings with family and friends”* [P5]).

#### 6. Child’s illness and the carers inevitable response

A broad theme emerged which included carers’ difficulties which were associated directly with the experience of their child’s illness (*“child becoming ill”* [P16], *“child’s illness/deterioration/changing condition”* [P11], *“lack of knowledge”* [P13], *“initial diagnosis and coming to terms with what this means to parents/families/life”* [P12]) and later adjusting emotionally to the child’s condition, their prognosis and the lack of control this brings (*“Unable to help their children change their condition*

*or stop the pain/symptom*” [P7], *“Unpredictability of life limiting condition”* [P19], *“realisation that their child is nearing end of life/going to die”* [P 3] and *“Anticipatory grief”* [P6]).

#### 7. Difficulties with accessing appropriate medical care for child

Participants commented on the frequent difficulties that carers face in accessing appropriate care and resources. This included experiences such as poor communication between medical professionals (*“poor communication between GP and hospital MDT”* [P11], *“Having to repeat their story time and time again to different professionals”* [P15]), carers needing to advocate for sufficient services and equipment for their child (*“Having to fight for numerous things for their child e.g. equipment, adaptations, etc.”* [P10]), a lack of appropriate health care resources (*“not having sufficient services”* [P15], *“don’t have right equipment at home to care for their children”* [P10], *“Chasing supplies, medications/prescriptions”* [P6]) and systems that create barriers to accessing care (*“Lack of funding to provide adequate support/equipment in the community”* [P19], *“Care packages breaking down”* [P18], *“Recruiting carers”* [P12]).

#### ▪ **Topics that carers find difficult to discuss**

Participants (Hospice staff) identified a number of issues which, in their experience, carers had found difficult to discuss. Six distinct themes emerged from the data provided. These included: ‘Asking for help and reassurance’, ‘The child’s ongoing treatment and care’, ‘End of life issues’, ‘Carer emotional wellbeing and coping’, ‘Relationship difficulties and family wellbeing’ and ‘Financial difficulties’.

#### 1. Asking for help and reassurance

Participants commented on carers difficulties in asking for help from professionals and reassurance regarding the quality/provision of their own care for their child: *“Asking for help and considering this as failing as a parent”* [P15], *“Am I doing all right?”* [P6], *“Things that they need”* [P10].

## 2. The child’s ongoing treatment and care

Data also indicated that carers struggle to discuss ongoing care and treatment including carers struggling to speak about *“the care they receive at home”* [P18], *“Medication”* [P12] and *“help with physical care”* [P12].

## 3. End of life issues

Participants highlighted struggles that carers have in discussing end of life issues such as *“end of life/anticipatory care”* (P7), *“the life limiting aspects of [the] child’s condition- anticipatory grief”* (P17), *“future without their child”* (P17) and *“planning their child’s funeral”*. (P12).

## 4. Carer emotional wellbeing and coping

Carer emotional wellbeing and coping emerged as a theme for which carers struggle to speak to others about (*“Their mood”* [P1], *“Anxiety, depression”* [P5], *“things that will benefit them/they need”* [P10], *“emotional issues”* [P11] and *“How they are coping”* [P1]).

## 5. Relationship difficulties and family wellbeing

Participants highlighted *“relationship issues”* [P3] and role difficulties as topics which carers struggle to share (*“family issues”* [P11], *“sense of embarrassment that [they] cannot provide for family wellbeing”* [P17]).

## 6. Financial difficulties

The theme of *“financial difficulties”* (P7) was a topic that multiple participants felt carers were unable or less free to discuss with others (*“financial concerns/issues”* [P2, P17], *“Money matters”* [P18]).

### ▪ Sources of support which carers find beneficial

Participants reported sources of support carers found beneficial in helping them to manage difficulties encountered in their caring role. Eight themes emerged from the data:

These included: 1. Respite, 2. Care at Home/Home help (*“Overnight support* [P2], *“help in the home – domestic chores”* [P7] ), 3. Financial Support, 4. Friends and family, 5. Spiritual support, 6. Peer support from other carers (*“Time with other families who are facing similar situations”* [P19], *“Shared experience with other families in hospice”* [P3]). 7. Professional Therapeutic support (*“counselling”* [P1], *“therapy”* [P5], *“direct 1:1”* [P 6], *“solution focussed support”* [P10]), 8. Consistent and accessible medical staff (*“Professionals that the ability to really listen and then act”* [P15], *“Someone to be contactable easily”* [P9], *“Continuity of staff”* [P11]).

Participants also spoke about the characteristics and qualities of supports which carers find helpful. Comments provided mainly focused on a supporters ability to listen and offer a non-judgemental ear (*“Someone they can sound off to”* [P9], *“Someone who listens without always having an opinion”* [P8], *“A listening ear”* [P2]).

Themes which emerged from the data (e.g. time management, self-care/support, relationship difficulties, communicating with health care professionals, etc.) were

used to create new content and modules specifically tailored for carers of young people with chronic illness. This content was then added to a pre-existing cCBT course (Living Life to the Full) which was then trialled in a feasibility study by parents/carers.

## **Study 2: Online intervention for Carers**

### **AIMS**

1. Assess different methods of recruiting participants for the online CBT course.
2. Establish participant completion rates of outcome measures/questionnaires at baseline and at post-treatment (6 weeks).
3. Establish the likely effectiveness of the online CBT course in reducing participant psychological distress.
4. Investigate participant use of and satisfaction with the online CBT course.

## **METHODS**

### **Participants**

Eligible participants included carers of children or young people with life-limiting or chronic medical conditions (i.e. present for more than 3 months) who resided within the UK. Individuals were excluded from the study if they: 1) did not consent 2) did not provide their GP details 3) did not care for a young person with a chronic medical condition 4) cared for a young person with solely a chronic mental health condition 5) indicated that they were experiencing suicidal thoughts nearly every



day on Patient Health Questionnaire-9 (PHQ9; Kroenke, Spitzer and Williams, 2001).

## **Recruitment**

Participants were recruited between January 2017 and July 2017 using a variety of approaches. Staff at Robin House Children's Hospice distributed brief information leaflets and posters to carers during respite stays (See Appendices 4 and 5). A social media page on Facebook was created to promote the study. A marketing company was also employed to target carers using the social media page to recruit carers from settings outside the hospice.

Adverts invited participants to either email the primary researcher for further information or to access an online recruitment website created using the website programme SurveyMonkey. The website contained a participant information sheet, a consent form and baseline questionnaires (See Appendices 6, 8 and 10). Baseline questionnaires asked participants to rate their mood, level of day to day functioning and to provide some basic information about themselves and the young person they cared for (See Appendix 3.7).

## **Consent**

Informed consent was obtained and recorded online using the recruitment website. Participants were asked to provide consent for their GP to be contacted by the primary researcher if results from their questionnaires indicated that they were at heightened risk of harm (i.e. if participants indicated on PHQ9 that they experienced thoughts of self-harm or suicide).

## **Procedures**

A Quasi Experimental design including pre and post comparisons without a control group was used to evaluate the feasibility and potential efficacy of the online course. After providing informed consent, participants were asked to give some basic demographic information about themselves, their caring duties and the individual/s they cared for. Participants were then asked to complete a number of baseline questionnaires including: self-reported levels of anxiety (General Anxiety Disorder-7; GAD-7, Spitzer et al., 2006); depression (Patient Health Questionnaire-9; PHQ9, Kroenke, Spitzer and Williams, 2001) and social/occupational functioning (Work and Social Adjustment Scale; WSAS, Mundt et al., 2002). Individuals who met the inclusion criteria were then given access to the 'Living Life to the Full for Carers' website via a hyperlink sent by email with additional information on how to register and navigate the site.

Six weeks post-recruitment, participants were emailed a hyperlink which enabled them to access the online recruitment website again. They were then asked to repeat the original baseline measures. Participants were also asked to complete a measure of their satisfaction with the online course: Client Satisfaction Questionnaire 8 (CSQ8, Larsen et al. 1979) and a number of brief questions about their experience of using the course. If participants failed to register, log onto the course or complete follow-up measures they were sent one reminder email.

## **Intervention**

The study trialled a tailored version of the online skills based course "Living Life to the Full" (Williams, 2009; [www.lltff.com](http://www.lltff.com)). In order to ensure the online course content was relevant for carers, data provided by hospice staff from

questionnaires and focus groups were analysed qualitatively to create themes/topics which were then used as the basis for modifying the course content.

The online course consisted of six core modules which aimed at assisting carers with difficulties including; low mood, anxiety and carer burnout through CBT techniques. The core modules included; 'Getting ready for change', 'Doing things that make you feel better', 'Looking at things differently', 'How to offer the support that they need', 'Managing anger and irritability' and 'Asking for what you need'. Modules were adapted to include illustrations and examples relevant to carers of children with chronic conditions.

The online course also included five optional modules which aimed to support specific difficulties including: drinking, smoking, sleep, sex and eating well and a number of "You Time Modules" which took approximately 5 – 10 minutes to complete and included helpful hints to enhance wellbeing.

Each core module consisted of a slideshow accompanied by audio narration. Participants also had access to e-books addressing a range of wellbeing topics and downloadable worksheets linked to each module (See Appendix 3.8). Participants were given the option of: choosing to work through modules in order, completing modules in their own chosen order or to only complete modules which were relevant to them. The online course permitted participants to stop a module at any point and return to the site at an alternative time. Material could also be revisited once completed.

Participants received personalised weekly support emails from an independent researcher (HB) for 6 weeks to provide assistance with course engagement and use. A standardized email template (See Appendix 3.15) was used and

individually modified for each email sent. The independent researcher had access to the course to monitor each participant's weekly progress. Support emails aimed to encourage participant progress and answer possible queries regarding the use of the course.

## **Measures**

Primary outcome measures included: the ability to recruit and retain participants, participant use and satisfaction with the online course and establishing baseline questionnaire completion rates.

Secondary outcome measures included: self-reported levels of anxiety (GAD-7); depression (PHQ9) and social/occupational functioning (WSAS). The GAD-7, PHQ9, WSAS were selected due to good levels of inter-rater reliability and validity and their ease of use for participants.

Participant satisfaction with the course was assessed through results from the CSQ-8 (Larsen et al., 1979) and additional open ended questions of acceptability and usage developed by the research team (See Appendix 3.14).

Participant demographic data was obtained through an online questionnaire developed by the research team (Appendix 3.7).

## **Data analysis**

Descriptive statistics were reported to describe participant sample characteristics. All statistical analyses were calculated using SPSS Version 21 (IBM Corp., 2012). Mann-Whitney U, Fisher's exact test and Chi-Square tests were performed to explore potential demographic differences and differences in secondary outcome

measures at baseline between participants who logged on, did not log on and those that did not complete follow up measures.

Wilcoxon signed rank tests were used to examine changes in secondary outcome measures at pre-intervention and at 6 week follow-up.

### **Ethical Approval**

The study was approved by the University of Glasgow Medical and Veterinary and Life Sciences ethics panel (Approval date: 14/12/16, Project Reference Number: 200160046; see Appendix 3.13).

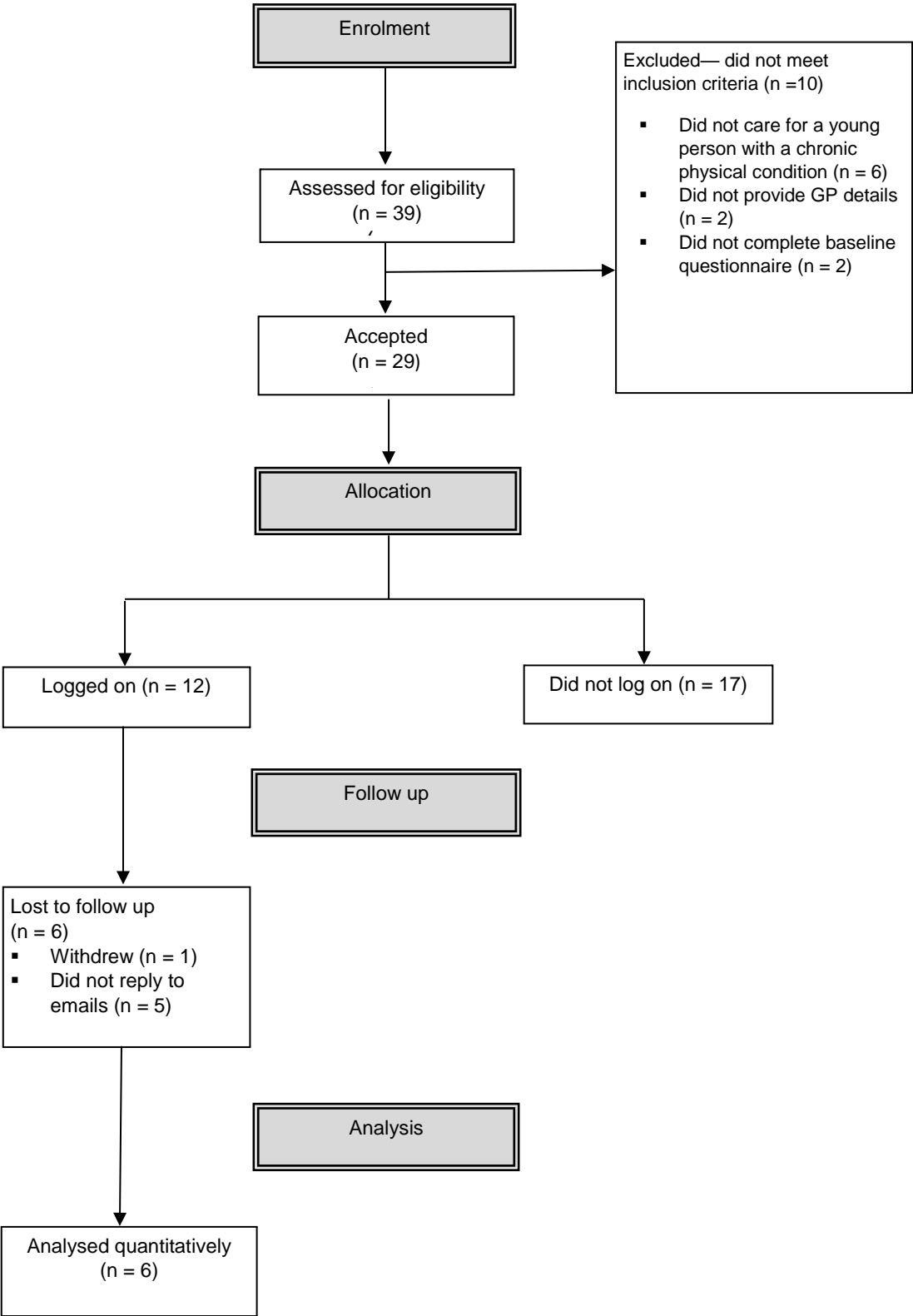
## **RESULTS**

### **Recruitment Methods**

39 individuals consented to participate and completed the baseline questionnaire. 29 of these participants (84.6%) met the inclusion criteria and were invited to participate fully in the study (see Figure 1).

Over half of the participants were recruited via social media advertisements on Facebook (55.2%, n=16; see Table 2). Advertisements placed in LLTTF email updates sent to current LLTTF programme users and on the LLTTF Website recruited another 20.7% (n = 6) and 3.4% (n = 1) respectively. Hospice staff, through their discussions with parents and carers during admission to the children's hospice, recruited 10.3% (n=3) of participants. Finally, 1 (3.4%) participant was recruited through the hospice Newsletters/Posters and 2 more (6.9%) were recruited through word of mouth from other organisations/family/friends.

**Figure 1:** Participant Flow Chart



**Table 2:** Recruitment Methods

Recruitment Methods	Total n = 29	%
Social Media	16	55.2
Advertisements within 'Living Life to the Full' email updates	6	20.7
Advertisements on the 'Living Life to the Full' website	1	3.4
Hospice Staff	3	10.3
Hospice Newsletter/Poster	1	3.4
Word of Mouth	2	6.9

### Sample Characteristics

Participants were recruited from across the UK; 44.8% (n = 13) were Scottish; 48.3% (n = 14) were English and 6.9% (n = 2) were from Northern Ireland. All participants provided direct care for children/young people with either a chronic medical condition or life limiting illnesses. All participants reported being of White ethnicity. The majority of participants were female (96.6%, n = 28), full time carers (44.8%, n = 13) who were either married or cohabiting with a partner (65.5%, n = 19). The majority of participants reported that they were a parent (96.6%, n = 28) and the primary caregiver (96.6%, n = 28) to the child/young person that they cared for.

A significant proportion reported that they had received support for mental health difficulties in the past (72.4%, n = 21) and 37.9% (n = 11) reported that they were currently receiving support for their mental health. Nearly half of the participants (48.3%, n = 14) reported that they were currently taking medication for mental health difficulties.

On average participants reported that they spent 21.3 hours (SD = 7) per day caring for a child/young person with a chronic condition and that they had been caring on for an average of 7 years and 2 months (SD = 5.2 years).

Baseline GAD-7 scores suggested that 17.2% (n = 5) fell within the 'normal' range; 41.4% (n = 12) had 'mild anxiety'; 24.1% (n = 7) had 'moderate anxiety' and 17.2% (n = 5) had 'severe anxiety' symptoms. Baseline PHQ-9 scores indicated that 10.3% (n = 3) fell within the 'normal' range; 34.5% (n = 10) had 'mild depression'; 24.1% (n = 7) had 'moderate depression'; 20.7% (n = 6) had 'moderately severe' depression and 10.3% (n = 3) had 'severe' depression.

Baseline WASAS scores suggested that 24.1% (n = 7) fell within the 'sub-clinical' range; 24.1% (n = 7) experienced 'significant' functional impairment and 51.7% (n = 15) experienced 'moderately severe' functional impairment.

**Table 3:** Demographic characteristics of the sample

Demographic characteristics	Total n = 29	Logged in n = 12 (41.4%)	Did not log in n = 17 (58.6%)	Significance (p-value)
<b>Age</b>				
25 - 34	5 (17.2)	2 (16.7)	3 (17.6)	t = 1.891, df = 27, P = .069
35 - 44	13 (44.8)	4 (33.3)	9 (52.9)	
45 - 54	10 (34.5)	5 (41.7)	5 (29.4)	
55 - 64	1 (3)	1 (8.3)	0 (0)	
<b>Gender</b>				
Male	1 (3.4)	1 (8.3)	0 (0)	$\chi^2$ (1, N=29) = 1.467, exact P = .414
Female	28 (96.6)	11 (91.7)	17 (100)	
<b>Marital Status</b>				
Single	2 (6.9)	9 (75)	10 (58.8)	$\chi^2$ (2, N=29) = 1.742, P = .499
Married/Living with partner	19 (65.5)	3 (25)	5 (29.4)	
Separated/Divorced	8 (27.6)	0 (0)	2 (11.8)	
<b>Working Status</b>				
Full time employed	5 (17.2)	5 (41.7)	0 (0)	$\chi^2$ (4, N=29) = 13.07, exact P = .003
Part-time employed	9 (31)	2 (16.7)	7 (41.2)	
Self-employed	1 (3.4)	1 (8.3)	0 (0)	
Long-term sick leave	1 (3.4)	1 (8.3)	0 (0)	
Full time carer	13 (44.8)	3 (25)	10 (58.8)	



<b>Own physical disability</b> Yes No	7 (24.1) 22 (75.9)	2 (16.7) 10 (83.3)	5 (29.4) 12 (70.6)	$\chi^2$ (1, N=29) = .624, P = .665
<b>Receiving support for Mental Health</b> Yes No	11 (37.9) 18 (62.1)	5 (41.7) 7 (58.3)	6 (35.3) 11 (64.7)	$\chi^2$ (1, N=29) = .121, P = .728
<b>Past support for Mental Health</b> Yes No	21 (72.4) 8 (27.6)	10 (83.3) 2 (16.7)	11 (64.7) 6 (35.3)	$\chi^2$ (1, N=29) = 1.222, P = .408
<b>Current medication for Mental Health</b> Yes No	14 (48.3) 15 (51.7)	6 (50) 6 (50)	8 (47.1) 9 (52.9)	$\chi^2$ (1, N=29) = .24, P = .876
<b>Average hours caring each day</b> 0 – 6 7 – 12 13 – 18 19 – 24 No information	1 (3.4) 6 (20.7) 7 (24.1) 13 (44.8) 2 (6.9)	1 (8.3) 4 (33.3) 5 (41.7) 2 (16.7) 0 (0)	0 (0) 2 (11.8) 2 (11.8) 11 (64.7) 2 (11.8)	U = 36.0, N1=12, N2=15, p=.007
<b>Other children to care for</b> Yes No	19 (65.5) 10 (34.5)	7 (58.3) 5 (41.7)	12 (70.6) 5 (29.4)	$\chi^2$ (1, N=29) = .468, P = .694

No significant demographic differences were found between those participants who did and did not log onto the course (see Table 3) apart from working status and average hours caring. Participants who did not log in were more likely to be full-time carers and not in employment and cared more hours per day than those who did log in.

Tests of normality were carried out on change scores between the secondary outcome measures at baseline and at follow-up. Distribution histograms, Shapiro-Wilk tests and box plots indicated that the data was not normally distributed. No significant differences in baseline scores were identified between those logged onto the course, those who did not (See Table 4).

**Table 4:** Median Baseline scores on Secondary outcome measures

	<b>Total Sample (n=29)</b>	<b>Logged on (n=12)</b>	<b>Did not Log on (n=17)</b>	<b>Significance p-value</b>
	<b>Median (IQR)</b>	<b>Median (IQR)</b>	<b>Median (IQR)</b>	
GAD7	9 (6 - 13)	11 (7 – 14)	7 (6 – 11)	.195
PHQ9	12 (7 – 16)	12.5 (7 – 18)	9 (6 – 14)	.616
WASAS	23 (12 – 27)	23.5 (19 – 26)	19 (8 – 29)	.744

### Attrition and Adherence

Follow-up data was available for 20.7% (n = 6/29) of participants; giving an overall attrition rate of 79.3% from those recruited. Overall, 12 participants (41.4%) logged onto the website. One withdrew from the study after logging onto the online course due to personal circumstances.

From the participants that initially logged onto the course (n = 12), 91.7% (n = 11) of participants started the course (defined as any participant who commenced any of the modules or downloaded any e-books, in any order) and 16.7% (n = 2) completed all of the six core modules within the given time period (6 weeks). Those who started the course (n = 11), commenced an average of 3 core modules (SD = 2.3) and completed an average of 1.9 (SD = 2.3). A proportion of participants who commenced the course downloaded at least one e-book (63.6%, n = 7); accessed at least one 'Youtime' module (45.5%, n = 5) and accessed at least one additional module (27.3%, n = 3).

Participants logged onto the course an average of 5.2 times (SD = 3.5) and spent a mean of 108.2 minutes (SD = 107.1) using the online course.

**Table 5:** Participant Module completion rates

<b>Course use</b>	<b>n</b>	<b>%</b>
Started the course	11/29	37.9
Module 1 completed	7/11	63.6
Module 2 completed	4/11	36.4
Module 3 completed	3/11	27.3
Module 4 completed	3/11	27.3
Module 5 completed	3/11	27.3
Module 6 completed	3/11	27.3
All core modules completed	2/11	18.2
Accessed at least 1 optional module	3/11	27.3
Accessed at least 1 'You time' Module	5/11	45.5
Downloaded at least 1 eBooks	7/11	63.6

### Email contact per participant

After logging into the course participants were given 6 weeks to complete the course. Each participant received 6 automatic emails (1 per week). Participants sent an average of 1.8 emails (SD = 1.8, range 0 - 5) each in response to personalised or automated emails.

### Therapeutic Change

As a feasibility trial, the study was insufficiently powered to detect small to moderate significant differences in scores over time. Exploratory analyses were, however, conducted to establish an estimate of potential effect. Wilcoxon signed rank tests showed no significant changes in scores on the GAD-7 ( $z = -1.83$ ,  $p = .068$ ), PHQ9 ( $z = -1.36$ ,  $p = .176$ ) or WASAS ( $z = -1.89$ ,  $p = .058$ ). Although statistically insignificant, change scores in secondary outcome measures indicated a general trend of participants experiencing less anxiety (mdn =6.5, IQR = 3.75 –

10.75, n = 6) and functional impairment (mdn =15.5, IQR = 11.25 – 16.75, n = 6) than at baseline (mdn =10, IQR 5.5 – 14.5, n = 6), (mdn = 19, IQR = 15.25 – 22.75, n = 6), respectively.

**Table 6:** Change in secondary measures over time

	<b>Baseline Median (IQR) n = 6</b>	<b>Post-treatment Median (IQR) n = 6</b>	<b>Significance p-value</b>
GAD7	10 (5.5 -14.5)	6.5 (3.75 – 10.75)	.068
PHQ9	7 (6.25 – 15.25)	6.5 (3 – 10.75)	.176
WASAS	19 (15.25 – 22.75)	15.5 (11.25 – 16.75)	.058

### **Participant Satisfaction**

Participants who completed the CSQ-8 reported a moderate to high level of satisfaction with the online course (Mean = 24.5/31, SD = 3.1, n = 6). All participants reported that the online course met either most or all of their needs (n =6). Most participants reported that the course helped them manage their problems more effectively and stated that they would come back to the online course again (83.3%, n=5/6). All participants indicated that they would recommend the online course to a friend who was in need of similar help.

Participants who provided follow-up data were given the opportunity to provide comments regarding their experience of using the online course. Three broad themes were identified using a thematic analysis approach following Braun and Clarke's (2006) approach. These included: the content/usability of the course, online delivery as a mode of accessing support and experience of email support.

- **Content and usability of the online course**

Participants were positive about the overall content describing the course as including *“good topics”, “Useful advice and tips”* (P25) and being *“easy to use and follow”* (P22). One participant stated that they *“definitely [thought] that a course like this is needed for parents and carers”* (P25) and another stated that it was *“helpful and reminded [them] of techniques from counselling”* (P20).

One participant highlighted that they *“thought the actual courses might be longer”* (P22). Another participant highlighted the benefits of the accessibility of the course but also referred to its lack of individualised elements; *“It was good as I didn’t have to make an appointment or go to sessions for a 1-1 session but think I may have got more out of a 1-1 session as it would be more tailored to suit me personally”* (P22).

- **Online as a mode of delivery for carer support**

Participants were positive about receiving support online. Almost all of the participants commented on the benefits that an online approach provided in overcoming difficulties of time constraints resulting from caring duties when attempting to seek support; *“Online is the only way I could fit this in”* (P23), *“It’s better online due to time constraints”* (P22). Participants also commented on the flexibility that the unlocked, online course created; *“I liked that I could do it at my own leisure”* (P20), *“being able to pick my own time to do it”* (P24) and *“dip in and out of”* (P21).

Despite the online mode of delivery being welcomed and assisting some with the difficulties carers face in accessing support, participants still highlighted difficulties

with finding time to complete the online course; *“Online means that you can do the course at your own pace but finding the time is difficult”* (P25), *“Even though it was online I still struggled to find time to sit and do it”* (P22) and *“I just didn’t have enough time to follow course properly this time. I would like to try it again”* (P21).

One participant offered a possible suggestion for increasing the course’s accessibility (*“I liked the course itself, perhaps being able to access it on an app on a smartphone would be easier than going online on a computer”* [P25] ).

- **Email support**

Participants described receiving regular emails as beneficial, particularly in terms of an ongoing reminder and as a form of encouragement (*“Good props to remind me to take time for myself”* [P20], *“It was good encouragement and also a reminder to keep going with the course”* [P25]). One participant suggestion for improving the emails was to shorten their length as they were described as having *“too many words”* (P24).

## **DISCUSSION**

To the authors knowledge, this is the first study to create, offer and assess the feasibility of a cCBT skill based course for carers of children with a broad range of chronic and life limiting illnesses.

Information gathered from completed questionnaires and focus groups by hospice staff provided rich and detailed qualitative data regarding carers’ experiences and difficulties. Themes that emerged from this data were used to adapt the cCBT course to include topics which were relevant to carers’ needs. Themes which

emerged from the qualitative data from hospice staff were consistent with carer stressors reported in previous research (Smith, Cheater and Bekker, 2015; Barlow & Ellard, 2006; Cousino & Hazen, 2013) and qualitative results from carers indicated positive feedback regarding the course's content.

Online advertising was the most successful method of recruiting carers with a total of 79.3% (n = 23) participants being recruited from social media, emails and websites. A recent systematic review suggested that social media is a viable and cost effective method for recruiting participants for psychosocial research. Results also indicated that the social media site, Facebook, can be used to obtain samples similarly representative to those recruited via more traditional methods (Thornton et al. 2016). It is unclear, however, how representative the current study's sample is. Research by Blackburn, Read and Hughes (2005) indicated that significant numbers of carers may not be internet users and that factors such as age, gender, socio-economic status and caring responsibilities may shape internet usage. In the current study a low proportion of male participants and those aged over 55 years were recruited. It would, therefore, be important to discuss alternative recruitment methods with Fathers and Grandparents in order to ensure a more representative recruitment sample in future trials.

Recruitment to the study was generally slow. A recent survey of adult carers of disabled children by Blackburn and Read (2005) showed a high proportion had previously used the internet (75%). The reasons for low recruitment rates are unknown, however, limited time may act as barrier to accessing or delaying help seeking, as had been indicated in previous literature (Acton, 2002; Carers UK, 2012). Significant effort for recruiting was invested by the primary researcher into liaising with local children's hospice staff with the hope of promoting the online

course and increasing recruitment. Few participants were recruited via hospice staff (10.3%, n = 3). Interestingly, research by Czuchta and McCay (2001) reported a similar phenomenon with social networks having high importance in carer help-seeking behaviour and professional support often being sought last. It may, therefore, be of benefit for researchers of future trials to investigate alternative recruitment methods in addition to social media (e.g. recruiting through carer support groups) to enhance overall recruitment rates.

Attrition was significantly higher in the current study (79.3%, n = 23) in comparison to research using similar online courses with carers (27%) (Hoyle et al., 2013). Of those who logged onto the course, treatment uptake was good (91.7%, n = 11), however, adherence to the course was relatively poor with only 16.7% (n = 2) of participants completing all elements of the course. Reasons for non-adherence are unknown, however, qualitative results indicated that insufficient time amongst caring duties may have been a possible factor. In addition, qualitative results and comments made during email support indicated that some participants had difficulties with regular computer usage and would have preferred to access the course on a handheld digital device (e.g. a phone or a tablet). It is possible that lack of accessibility to a computer due to hospice stays and hospital admissions may have had a subsequent effect on adherence and carer motivation to complete the course, therefore, affecting retention rates.

Of the participants who completed follow-up measures, the majority reported high satisfaction with the course. Qualitative results from participants highlighted how participants valued email support from the research team especially in terms of providing motivation and reminders. This is line with previous research which has



indicated that regular guided support during online interventions can enhance clinical outcomes and adherence (Andersson, and Titov, 2014).

One aim was to investigate the acceptability of offering an online psychological intervention for carers. Participants appeared to appreciate the flexibility that an online approach gave them in increasing accessibility to support and overcoming the barrier of limited time. However, it proved difficult to recruit carers to the study and therefore treatment uptake was low. A recent survey of adult carers of disabled children by Blackburn and Read (2005) showed carers often used the internet for tasks including obtaining information about caring, emailing, ordering equipment and shopping online, suggesting that online resources may be acceptable to a high proportion of carers. Blackburn and Read (2005) did, however, highlight a digital divide with those not using the internet more likely to be living in rented accommodation, be unemployed and be lacking access to a computer at home. This is especially relevant as caring has been linked to higher rates of unemployment and increased risk of poverty (Francesca et al, 2011). This study therefore, indicates that the provision of mental health support online may benefit some due to the flexibility it creates in accessing support at home and at any time of the day. However, further research is required to identify ways of supporting carers who do not have access to the internet and are not in a current position to prioritise their own mental health.

A number of limitations can be identified within the current study. The content of the adapted cCBT course was tailored for carers based on information gathered from professionals working within hospice settings. Many of the topics suggested for inclusion within the course were in line with carer stressors reported in previous research (Smith, Cheater and Bekker, 2015; Barlow & Ellard, 2006; Cousino &

Hazen, 2013). However, as the course was adapted using information provided by professionals rather than carers, the topics included may not have been a fully accurate representation of the carer experience. This could, therefore, have reduced the appropriateness and accessibility of the course content. Future research into carers' experiences may assist in ensuring the content is fully appropriate for their needs.

Due to low recruitment rates and the study being insufficiently powered, analyses were unable to detect small to moderate treatment effects. Although there was a general trend towards a reduction in anxiety rates and functional impairment at follow up, the lack of a control group makes it difficult to establish if this is a true treatment effect or not. A future, more substantiate RCT with an adequately powered sample would assist in establishing the accessibility and potential clinical effect cCBT in reducing mental health difficulties in carers of children with chronic conditions.

Participants who completed follow up measures and measures of treatment satisfaction had varying rates of course adherence (ranging from 0 – 6 modules completed). There is, however, still a potential risk of qualitative results being biased. Participants who had a positive experience of the cCBT course may have been more motivated to complete follow-up measures, therefore creating a positive bias in qualitative results regarding treatment satisfaction and acceptability. Future research exploring participant intervention experience and satisfaction would benefit from implementing a structured sampling frame to capture a range of participant experiences.

## **CONCLUSION**

cCBT adapted for carers of children with chronic and LLI may be an acceptable way of increasing access to mental health supports for those whose caring duties reduce the time/flexibility they have to prioritise their own health care. However, challenges in recruiting and retaining carers suggests that mental health support offered online may only be an acceptable method of delivery for some carers and alternative modes of delivering support should be explored for those who do not have regular access to the internet. Retention rates for course may be increased by amending the cCBT course to enable it to be used on handheld digital devices through a mobile phone application program (i.e. app) and enabling modules to be downloadable and printable. This would increase its accessibility by making the course material available offline as well as on portable devices which carers could access when they are not at home or unable to sit at a computer.

Rich qualitative data gathered from hospice professionals supported the adaptation of a pre-existing cCBT course to suit the needs of carers of children with chronic and LLI. A mixed method approach of both qualitative and quantitative analyses enabled a rich array of information to be gathered regarding the benefits and drawbacks of providing mental health support online. Low recruitment rates resulted in difficulties estimating the potential effectiveness of the cCBT course in reducing symptomology. However, a more substantive pilot study should be undertaken in the future to investigate the acceptability of an updated version of the course, establish its potential effectiveness with randomization of participants, investigate alternative forms of recruitment and explore the course's potential cost effectiveness.

## **CONFLICT OF INTEREST**

Professor Chris Williams is the author of “Living Life to the Full”, the cCBT course adapted in this study. He is a shareholder and director of a company that commercialised this and online resources.

## REFERENCES

- Acton, G. J., 2002. Health-promoting self-care in family caregivers. *Western Journal of Nursing Research*, 24(1), pp.73-86.
- Andersson, G. and Titov, N., 2014. Advantages and limitations of Internet-based interventions for common mental disorders. *World Psychiatry*, 13(1), pp.4-11.
- Arksey, H. and Hepworth, D., 2000. *Carers' Needs And The Carers Act: An evaluation of the process and outcomes of assessment*. Social Policy Research Unit.
- Barlow, J.H. and Ellard, D.R., 2006. The psychosocial well-being of children with chronic disease, their parents and siblings: An overview of the research evidence base. *Child: care, health and development*, 32(1), pp.19-31.
- Becker, S., 2000. Carers and indicators of vulnerability to social exclusion. *Benefits*, 28, pp.1-4.
- Blackburn, C. and Read, J., 2005. Using the Internet? The experiences of parents of disabled children. *Child: care, health and development*, 31(5), pp.507-515.
- Blackburn, C., Read, J. and Hughes, N., 2005. Carers and the digital divide: factors affecting Internet use among carers in the UK. *Health & Social Care in the Community*, 13(3), pp.201-210.
- Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), pp.77-101.
- Burton, L.C., Zdaniuk, B., Schulz, R., Jackson, S. and Hirsch, C., 2003. Transitions in spousal caregiving. *The Gerontologist*, 43(2), pp.230-241.

Cadman, D., Rosenbaum, P., Boyle, M. and Offord, D.R., 1991. Children with chronic illness: family and parent demographic characteristics and psychosocial adjustment. *Pediatrics*, 87(6), pp.884-889.

Carers UK, 2012. In Sickness and In Health. A survey of 3,400 UK carers about their health and wellbeing [pdf]. Available at: <https://www.carersuk.org/for-professionals/policy/policy-library/in-sickness-and-in-health> [Accessed on 3 April 2018].

Carers UK, 2015. *State of Caring 2015* [pdf]. Available at: <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015> [Accessed on 3 April 2018].

Carers, U.K., 2011. Valuing carers: calculating the value of carers' support. *London: Carers UK*.

Contact a Family, 2011. Forgotten families: The impact of isolation on families with disabled children across the UK. *Contact a Family, York*.

Cousino, M.K. and Hazen, R.A., 2013. Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, 38(8), pp.809-828.

Czuchta, D.M. and McCay, E., 2001. Help-seeking for parents of individuals experiencing a first episode of schizophrenia. *Archives of Psychiatric Nursing*, 15(4), pp.159-170.

Dahlquist, L.M., Czyzewski, D.I., Copeland, K.G., Jones, C.L., Taub, E. and Vaughan, J.K., 1993. Parents of children newly diagnosed with cancer: anxiety, coping, and marital distress. *Journal of pediatric psychology*, 18(3), pp.365-376.

Davies, B., Steele, R., Collins, J.B., Cook, K. and Smith, S., 2004. The impact on families of respite care in a children's hospice program. *Journal of palliative care*, 20(4), pp.277.

Eccleston, C., Fisher, E., Law, E., Bartlett, J. and Palermo, T.M., 2015. Psychological interventions for parents of children and adolescents with chronic illness. *The Cochrane database of systematic reviews*, 4, pp.CD009660.

Eccleston, C., Palermo, T.M., Fisher, E. and Law, E., 2012. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane database of systematic reviews (Online)*, 8, pp.CD009660.

Francesca, C., Ana, L.N., Jérôme, M. and Frits, T., 2011. *OECD health policy studies help wanted? Providing and paying for long-term care: providing and paying for long-term care* (Vol. 2011). OECD Publishing pp. 85 – 117.

Grover, M., Naumann, U., Mohammad-Dar, L., Glennon, D., Ringwood, S., Eisler, I., Williams, C., Treasure, J. and Schmidt, U., 2011. A randomized controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa. *Psychological Medicine*, 41(12), pp.2581-2591.

Hirst, M. A. & Hutton, S., 2000, Informal care over time. *Benefits*, vol 28, pp. 9-12.

Howard, M., 2001. *Paying the price: carers, poverty and social exclusion* (Vol. 104). CPAG.

Hoyle, D., Slater, J., Williams, C., Schmidt, U. and Wade, T.D., 2013. Evaluation of a web-based skills intervention for carers of people with anorexia nervosa: A randomized controlled trial. *International Journal of Eating Disorders*, 46(6), pp.634-638.

IBM Corp, 2012. IBM SPSS Statistics for Windows (Version 21). [computer program] Available at: <https://www.ibm.com/analytics/us/en/technology/spss/> [Accessed on 3 April 2018].

Keeley, B. and Clarke, M., 2002. Carers Speak Out Project. *Report on findings and recommendations. London: Princess Royal Trust for Carers.*

Kroenke, K., Spitzer, R.L. and Williams, J.B.W., 2001. The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), pp.606–613.

Larsen, D.L., Attkisson, C.C., Hargreaves, W.A. and Nguyen, T.D., 1979. Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning*, 2(3), pp.197–207.

Lewis, M. and Prescott, H., 2006. Impact of life-limiting illness on the family. *Oxford textbook of palliative care for children*, pp.154-178.

Maher, J. and Green, H., 2002. Carers 2000.

McCann, T.V., Lubman, D.I., Cotton, S.M., Murphy, B., Crisp, K., Catania, L., Marck, C. and Gleeson, J.F., 2012. A randomized controlled trial of bibliotherapy for carers of young people with first-episode psychosis. *Schizophrenia bulletin*, 39(6), pp.1307-1317.

Mundt, J.C., Marks, I.M., Shear, M.K. and Greist, J.M., 2002. The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry*, 180(5), pp.461-464.



Nelson, K.E., Hexem, K.R. and Feudtner, C., 2012. Inpatient hospital care of children with trisomy 13 and trisomy 18 in the United States. *Pediatrics*, 129(5), pp.869-876.

NHS Health and Social Care Information Centre, 2010. *Survey of carers in households in England 2009–10*. Leeds, England. Available at: <http://www.hscic.gov.uk/pubs/carersurvey0910> [Accessed on 3 April 2018].

NICE, 2009. Depression in adults: recognition and management (CG90) [pdf] Available at: <https://www.nice.org.uk/guidance/cg90/resources/depression-in-adults-recognition-and-management-pdf-975742636741> [Accessed 3 April 2018].

NICE, 2011. Generalised anxiety disorder and panic disorder in adults: management (CG113) [pdf] Available at: <https://www.nice.org.uk/guidance/cg113/resources/generalised-anxiety-disorder-and-panic-disorder-in-adults-management-pdf-35109387756997> [Accessed 3 April 2018].

Office for National Statistics. Social Survey Division. (2006). General Household Survey, 2000-2001. [data collection]. *3rd Edition*. UK Data Service. Available at: <http://doi.org/10.5255/UKDA-SN-4518-1> [Accessed on 3 April 2018].

Parker, G., 1993. *With this body: Caring and disability in marriage*. Buckingham, Open University Press.

Schulz, R., O'Brien, A.T., Bookwala, J. and Fleissner, K., 1995. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *The Gerontologist*, 35(6), pp.771-791.

Schulz, R., Visintainer, P. and Williamson, G.M., 1990. Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology*, 45(5), pp.181-191.

Sepulveda, A.R., Lopez, C., Macdonald, P. and Treasure, J., 2008. Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder. *International Journal of Eating Disorders*, 41(4), pp.318-325.

Smith, J., Cheater, F. and Bekker, H., 2015. Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expectations*, 18(4), pp.452-474.

Spitzer, R.L., Kroenke, K., Williams, J.B.W. and Löwe, B., 2006. A Brief Measure for Assessing Generalized Anxiety Disorder. *Archives of Internal Medicine*, 166(10), pp.1092 - 1097.

Thornton, L., Batterham, P.J., Fassnacht, D.B., Kay-Lambkin, F., Calex, A.L. and Hunt, S., 2016. Recruiting for health, medical or psychosocial research using Facebook: Systematic review. *Internet Interventions*, 4, pp.72-81.

Van Cleave, J., Gortmaker, S.L. and Perrin, J.M., 2010. Dynamics of obesity and chronic health conditions among children and youth. *Jama*, 303(7), pp.623-630.

Warner, N., 1995. Better Tomorrows? Report of a National Study of Carers and the Community Care Changes. *Carers National Association, London*.

## Chapter 3: Appendices

## Appendix 1.1: Authors guidance for submission to The International Journal of Care and Caring

Guidelines accessed July 2018 from:

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Submissions must be completely anonymised and uploaded without preliminary details, such as title, author, affiliations, abstract or keywords in the text file. All submissions will be subject to anonymous peer-review processes (unless stated otherwise) by referees currently working in the appropriate field.

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- British English spelling and punctuation is preferred.
- Non-discriminatory language is mandatory.
- Explanatory notes should be kept to a minimum. If it is necessary to use them, they must be numbered consecutively in the text and listed at the end of the article. Please do not embed notes in the text.
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- Tables and charts should be separated from the text and submitted in a Word or Excel file, with their placement in the text clearly indicated by inserting: 'Table X here'. Please provide numbers, titles and sources (where appropriate).
- Figures, diagrams and maps should be separated from the text and, ideally, submitted in an
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(Duffy et al, 2015)
- List all references in full at the end of the article and remove any references not cited in the text
- Book and journal titles should be in italics
- Website details should be placed at the end of the reference. Do not include dates of access to websites
- Spell out all acronyms in first instance.
-

## Appendix 2.1 Example Search Strategy for Systematic Review (Medline via Ovid)

- 1) (caregiver\* or famil\* or parent\* or mother\* or father\*).ti.
- 2) (Technolog\* or internet\* or computer\* or electronic\* or Software\* or Web\* or Online\* or Wireless\* or Wi?fi\*).ti.
- 3) (Evaluation or intervention or trial or pilot study).ab
- 4) (Child\* or teen\* or Adolescent\* or Paed\* or Pediatric\*).ti.
- 5) 1 and 2 and 3 and 4
- 6) limit 5 to (english language and "review articles" and yr="2003 -Current")
- 7) (caregiver\* or famil\* or parent\* or mother\* or father\*).ti
- 8) (Technolog\* or internet\* or computer\* or electronic\* or Software\* or Web\* or Online\* or Wireless\* or Wi?fi\*).ti.
- 9) (Evaluation or intervention or trial or pilot study).ab.
- 10) (Child\* or teen\* or Adolescent\* or Paed\* or Pediatric\*).ti
- 11) 7 and 8 and 9 and 10
- 12) limit 11 to (english language and "review articles" and yr="2003 -Current")

Appendix 2.2: Agreed CTAM Quality scores for all studies

<b>CTAM Questions</b>	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	Study 7	Study 8	Study 9	Study 10	Study 11
Q1) Is the sample: convenience (score 2), geographic cohort (score 5) or highly selective (score 0)	2	2	2	2	2	2	2	2	2	2	2
Q2) Is the sample greater than 27 participants in each treatment group (score 5) or based on described and adequate power calculations (score 5)	5	5	5	5	0	5	5	0	0	0	0
Q3) Is there true random allocation or minimisation allocation to treatment groups score (score 10)	10	0	10	10	10	10	10	0	10	10	10
Q4) Is the process of randomisation described (score 3)	3	0	3	3	3	3	3	0	3	3	3
Q5) Is the process of randomisation carried out independently from the trial research team (score 3)	3	0	0	0	0	0	0	0	0	0	0
Q6) Are the assessments carried out by independent assessors and not therapists (score 10)	10	10	10	10	10	10	10	10	10	10	10
Q7) Are standardised assessments used to measure symptoms in a standard way (score 6), idiosyncratic assessments of symptoms (score 3)	6	6	6	6	6	6	6	6	6	6	6
Q8) Are assessments carried out blind (masked) to treatment group allocation (score 10)	10	0	10	10	10	10	10	0	0	0	10



Q9) Are the methods of rater binding adequately described (score 3)	3	0	3	3	3	3	3	0	0	0	3
Q10) Is rater blinding verified (score 3)	0	0	0	0	0	0	0	0	0	0	0
Q11) TAU is a control group (score 6) and/or a control group that controls for non-specific effects or other established or credible treatment (score 10)	6	0	10	10	10	10	6	0	10	0	10
Q12) Is the analysis is appropriate to the design and the type of outcome measure (score 5)	5	5	5	5	5	5	5	5	5	5	5
Q13) The analysis includes all those participants as randomised (score 6) and an adequate investigation and handling of drop outs from assessment if the attrition rate exceeds 15% (score 4)	10	4	4	4	4	4	6	4	10	0	4
Q14) Was the treatment adequately described (score 3) and was a treatment protocol or manual used (score 3)	3	6	6	6	6	6	3	3	6	6	6
Q15) Was adherence to the treatment protocol or treatment quality assessed (score 5)	0	5	5	5	5	5	0	0	5	5	5
<b>Total (maximum score = 100)</b>	<b>76</b>	<b>43</b>	<b>79</b>	<b>79</b>	<b>74</b>	<b>79</b>	<b>69</b>	<b>30</b>	<b>67</b>	<b>47</b>	<b>74</b>

## Appendix 3.1: Carers Online Course Advertisement Example



College of Medical,  
Veterinary & Life Sciences

### DO YOU CARE FOR A CHILD WITH A CHRONIC MEDICAL CONDITION?



#### Do you feel like this?

Would you be interested in taking part in a research project by trialling a new online resource designed specifically to help parents and carers of children with chronic medical conditions who are experiencing low mood, stress or worry?

Living Life to the Full  
for Carers  
Research Project

## Appendix 3.2: Brief Study Information Leaflet for Participants (Carers)



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

### ***Living Life to the Full for Carers - Online Support Course***

#### **Research Project**

##### **What is it?**

The project is looking to recruit parents and carers of children with chronic/long term medical conditions. Participants will have the opportunity to trial a new online course aimed at supporting carers and parents of children with long term medical conditions.

The online course aims to help carers with difficulties like anxiety, worry, and frustration by learning and practicing new coping skills.

The course includes several online modules that you can read/listen to in your own time.

They include:

- ☐ Getting ready for change
- ☐ Doing things that make you feel better
- ☐ Looking at things differently and coping with negative thoughts
- ☐ How to offer the support your child need
- ☐ Managing anger and irritability
- ☐ Assertiveness and asking for what you need

There are additional resources on the site including optional modules and worksheets.

##### **What will I have to do as a Participant?**

You will be asked to complete three short questionnaires. One before starting the course, a second on completion and a third 2-4 weeks later.

You will be given the opportunity to work through the online course in your own time over the course of 6 weeks.

At the end you will also be asked to complete a brief questionnaire or telephone interview on your views about the course and how it could be improved for other parents/carers.

##### **Where do I get more information and how do I register to participate?**

If you are interested in participating please email the main researcher Lauren Manuel (Trainee Clinical Psychologist)

Email: [l.manuel.1@research.gla.ac.uk](mailto:l.manuel.1@research.gla.ac.uk)

Or

Read the Participant Information sheet on [www.surveymonkey.co.uk/r/LLTTF4Carers](http://www.surveymonkey.co.uk/r/LLTTF4Carers)

If you decide you want to participate you will be asked to complete a consent form and there will be a brief questionnaire to fill out.

After this has been completed, the researcher will then email you the website address and details on how to register and access the online course.

## **Participant Information Sheet**

### **Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy-based Support Packages**

*We would like to invite you to take part in a research study. Before you decide if you would like to participate you first need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Feel free to discuss the study with family and friends if you wish. Please contact us if there is anything that is not clear or if you would like more information.*

#### **What is the purpose of the study?**

Many people who care for a child or young person with a chronic health condition or life limiting illness can experience distress including low mood, stress and anxiety. Although parents and carers are often in contact with multiple health professionals it can be difficult for carers to access support for their own personal difficulties. This might be due to time restraints and difficulties in accessing services. To date there is limited research on support packages for parents and carers of young people with life limiting illnesses, which specifically target reducing carer distress. The current study examines a 6 week long online support course that teaches key coping skills based on a form of talking therapy called Cognitive Behavioural Therapy. It has been modified to reach out to carers/parents who may be experiencing high stress levels, anxiety or low mood.

The study will invite participants to take part in a 6 week long online course. Those who consent to participant in the study will also be asked to complete 3 sets of short questionnaires.

#### **What is the Online Course?**

The online course contains material derived from an existing widely used online resource. It is intended for use by carers and parents of young people experiencing a life limiting illness or chronic medical condition. The focus of the course is to deliver key coping skills through online modules with the aim to relieve mild to moderate symptoms of stress and low mood and enhance skills. Covered topics include problem solving, tackling low confidence, improving mood and challenging negative thinking. Specific topics will also include information on how to approach difficulties

that may arise whilst caring for a child with a life limiting illness.

### Why have I been invited to take part?

The study is offered to parents and carers of children and young people experiencing a life limiting illness and who may be experiencing difficulties associated with stress, low mood or just wish to enhance their coping skills.

Participation in the online course and completion of provided questionnaires will enhance the research team's insight into the potential usefulness of the course. The research team also hope to better understand how the online course may be tailored to better suit carers within a children's hospice settings.

### What will happen now?

If you choose to participate in the study, we will ask you to complete a consent form (please follow the link below). The consent form represents your agreement to take part in the study and agreement with the conditions of participation.

Once you have provided your consent you will be invited to complete four short questionnaires. One questionnaire will ask about your age, education/employment status, your carer status, the support you receive and whether you have been previously diagnosed with any mental health related condition, etc. You will also be asked to complete three short multiple choice questionnaires (less than 30 questions), which will ask about your mood. These initial questionnaires will help researchers to evaluate whether this study is right for you.

If the evaluation of the questionnaires shows that the study is not right for you, your participation will end here. If the study is suitable for you, the research team will then email you a 'getting started' guide detailing all necessary information to begin the study and log onto the site. You will have the option to contact the research team to get practical support with accessing the online package via email.

You will have access to the online course for 6 weeks. You will receive weekly support emails from the research team. After 6 weeks you will then be asked to fill in some of the questionnaires that you completed at the beginning of the study about symptoms of low mood and anxiety. You will also be asked to complete a brief questionnaire or telephone interview about your views on the online course. Finally, you will be asked to complete the questionnaires for a third time, four weeks after completing the course.

### What do I have to do?

- You will be asked to complete the three short questionnaires on three occasions.

- You will be given the opportunity to work through the online course in your own time over the course of 8 weeks.
- You will also be asked to complete a questionnaire or brief telephone interview about your views on the course and how it could be improved.

#### Do I have to take part?

You do not have to take part. If you decide to take part you are still free to withdraw at any time, without giving a reason.

#### Are there any potential benefits of taking part in this study?

It is hoped that you will learn practical coping skills as a result of completing the online course and that this will help to improve any symptoms of low mood, anxiety or stress that you have. We also hope to learn how effective the course is. Finally, your opinions about the online course will help us modify the site so that it is more suitable for other parents/carers who are experiencing symptoms of stress, low mood and anxiety.

#### Are there any disadvantages of taking part in this study?

Before and after the study you will be asked to complete a set of brief questionnaires about your mood and anxiety levels. Most people do not mind answering these questions, but some people may feel upset after completing them. It is important that we ask these questions to find out if the online package is effective in helping reduce negative symptoms. Sometimes when people find out more about low mood and stress they can feel worse to start with. However, this is usually just for a short time and most people feel better again quite quickly as they work through online courses like this one. In addition, if we are concerned about you we will contact your GP and contact you via email with information about other potential sources of support.

#### Will my taking part in the study be kept confidential?

The information you give is entirely confidential and will not be disclosed to anyone outside the immediate research team without your permission. However, if we are concerned at any stage about you, we will contact the CHAS team and your GP so that you can receive the support that is needed. We will therefore record your GP details and ask for your consent to allow us to do this when you start the study. We will not contact your G.P at any point without first contacting you.

All the information collected will be stored securely according to the Data Protection Act 1998.

#### What will happen to the results of the research study?

The results of the research will be written up in a PhD thesis and we also intend to present the results of the study as a scientific paper. No individuals will be identified in the research publications, which will contain only anonymised information. Additionally a copy of the results can be sent to you if you wish.

### Who is organising and funding the research?

The study is organised and funded by the Institute of Mental Health and Wellbeing at the University of Glasgow.

### Who has reviewed the study?

This study has been reviewed and approved by the College of Medical, Veterinary & Life Sciences Ethics Committee at the University of Glasgow.

### Who do I contact for further information?

More information about the study is available from the research team:

Lauren Manuel  
Email: [l.manuel.1@research.gla.ac.uk](mailto:l.manuel.1@research.gla.ac.uk)

Mental Health and Wellbeing  
Administration Building  
Gartnavel Royal Hospital,  
1055 Great Western Road,  
Glasgow,  
G12 0XH

Thank you for taking the time to read this and thinking about participating in the study!



## **Participant Information Sheet**

### **Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy-based Support Packages**

*We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Feel free to discuss the study with family and friends if you wish. Please contact us if there is anything that is not clear or if you would like more information.*

#### **What is the purpose of the study?**

Many people who care for a child or young person with a chronic health condition or life limiting illness can experience distress including low mood, stress and anxiety. Although parents and carers are often in contact with multiple health care professionals involved in their child's care it can be difficult for carers to access support for their own personal difficulties, whilst caring for a young person, due to time restraints and difficulties in accessing services. To date there is limited research on support packages for parents and carers of young people with life limiting illnesses, which specifically target reducing carer distress. The current study aims to develop and examine an online educational course that teaches key life skills based on a form of talking therapy called Cognitive Behavioural Therapy. It will be modified to reach out to carers/parents who may be experiencing high stress levels, anxiety or low mood.

The study initially aims to explore staff views on what topics and content would be useful and suitable to include in the online course. Staff will also be asked their opinions about how the online course could be modified to make it more accessible and appropriate for parents and carers.

After the course has been adapted and modified, parents and carers receiving support from Children's Hospice Association Scotland will be invited to participate in a feasibility study where they will be given the opportunity to complete the online course over 8 week. Those parents/carers who consent to participant in the study will also be asked to complete 3 sets of short questionnaires, which will help to assess the effectiveness and feasibility of the newly modified online course.



### **What is the Online Course?**

The online course contains material derived from an existing widely used online package. It is intended for use by carers and parents of young people experiencing a life limiting illness or chronic condition. The focus of the site is to deliver key life skills through online modules with the aim to relieve mild to moderate symptoms of stress and low mood and enhance skills. Topics covered include problem solving, tackling low confidence, improving mood and challenging negative thinking. Weekly automated emails accompany the course. Specific topics will also include information on how to approach difficulties that may arise whilst caring for a child with a life limiting illness.

### **Why have I been asked to take part?**

Participation in the study is being offered to support staff who work alongside carers and parents of children with life limiting illnesses. It is hoped that your experience and knowledge of the difficulties that parents/carer encounter will help inform content that may be suitable to include in the online course to make it more effective in reducing carer distress. We are also interested in your views on how to make the online course more accessible.

It is hoped that by completing the staff questionnaire and participating in a semi-structured group interview staff will enhance the research team's insight into the potential usefulness of the course and how it can be better tailored and delivered within a children hospice setting.

### **What will happen now?**

If you choose to participate in the study, you will be asked to fill in a short consent form. In this you will be asked to give informed consent, by agreeing to certain conditions and acknowledging that you are aware of what you are taking part in.

You will be asked to attend a brief presentation that will introduce you to the online course that will be adapted and modified for parents and carers of children with life limiting illness to help reduce carer distress.

After the presentation a short semi-structured group interview will take place where you will be asked about your opinions of the course and how you think it could be modified and adapted to be more effective and suitable for parents/carers. This interview will be recorded and transcribed so that valuable themes can be extracted to inform modifications to the online course.

You will finally be invited to complete a short questionnaire, which will ask you about your role, the type of support you offer to parents/carers, your opinions about content that may be helpful to include in the online course and your experience of what difficulties parents and carers face when caring for a child with a life limiting illness.

### **What do I have to do?**

- Attend a brief presentation about the online course that will be modified and offered to parents and carers at Robin and Rachel House.
- You will be given the opportunity to participate in a group interview about how best the online course could be adapted/modified to be more suitable for parents/carers.
- You will also be asked to complete a short questionnaire about possible content to include in the online course and your experience of the difficulties that parents/carers face.

### **Do I have to take part?**

You do not have to take part. If you decide to take part you are still free to withdraw at any time, without giving a reason.

### **Are there any potential benefits of taking part in this study?**

It is hoped that you will be able to provide the research team with invaluable insight and information about how to improve and modify the online course to make it more accessible and effective for parents/carers of children/young people with life limiting illnesses who may be experiencing carer distress. This will help us to develop a resource, which will then be used in a feasibility study with parents/carers who receive support from Children Hospice Association.

### **Are there any disadvantages of taking part in this study?**

Some individuals may experience some mild discomfort from participating in a brief group interview. There is however no pressure to participate in this and participants will be provided with the opportunity to provide opinions in written form via the questionnaire.

### **Getting extra support**

Additional supports are available as always, via your GP, NHS 24 or telephone support services such as The Samaritans or Breathing Space for any problems you face such as feeling distressed or if you are struggling.

### **Will my taking part in the study be kept confidential?**

The information you give is entirely confidential and will not be disclosed to anyone outside the immediate research team without your permission.

All the information collected will be stored securely according to the Data Protection Act 1998.

### **What will happen to the results of the research study?**

The results of the research will be used to inform the development and modification of the online course Living life to the full. Results from the full research will be written up in a PhD thesis and we also intend to present the results of the study as a scientific paper. A copy of the results can be sent to you if you wish. No individuals will be identified in the research publications, which will contain only anonymous information.

### **Who is organising and funding the research?**

The study is organised and funded by the Institute of Mental Health and Wellbeing at the University of Glasgow.

### **Who has reviewed the study?**

This study has been reviewed and approved by the College of Medical, Veterinary & Life Sciences Ethics Committee at the University of Glasgow.

### **Who do I contact for further information?**

More information about the study is available from the research team:

Lauren Manuel  
Email: study email address TBC

Mental Health and Wellbeing  
Administration Building  
Gartnavel Royal Hospital,  
1055 Great Western Road,  
Glasgow,  
G12 0XH

**Thank you for taking the time to read this and thinking about participating in the study!**

## Appendix 3.5: Consent Form (Carers)



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

### Living Life to the Full for Carers Online Support Course

#### Consent Form

Title of Study: Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy-based Support Packages

Name of Researchers: Professor Chris Williams & Lauren Manuel

*Fully informed consent is required for parents/carers to participate in the study. Please read the following statements and indicate whether you agree to them.*

1. I confirm that I have read and understand the participant information for the above study and have had the opportunity to contact the researchers to ask questions.

Agree ☐

Disagree ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

Agree ☐

Disagree ☐

3. I agree that the information I give will be kept if I am not eligible for the study.

Agree ☐

Disagree ☐

4. I agree to take part in the above study.

Agree ☐

Disagree ☐

5. I confirm I understand that additional supports are available for problems such as distress.

Agree ☐

Disagree ☐

6. I give consent for staff at CHAS to be notified if the research team are concerned about any risk to my wellbeing.

Agree ☐

Disagree ☐

7. I agree that my data collected during the study, including demographic details, are confidential and may be stored securely for up to 10 years at the University of Glasgow in a form that makes it impossible to identify me.

Agree ☐

Disagree ☐

NB. Online tick boxes will be used to signify consent - all boxes must be checked before participants can proceed to the next stage of the study.

## Appendix 3.6: Consent Form (Hospice Staff)

### Consent Form

**Title of Project:** Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy-based Support Packages

**Name of Researchers:** Professor Chris Williams and Lauren Manuel

**Name:**

**Age:**

**Job title/role:**

I confirm that:

1. I have read and understand the Participant information sheet for staff, version 1.1, dated 24/11/2016, for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in completing the written questionnaire. ☐
4. I agree to take part in a group interview. ☐
5. I agree that the data I provide during the study are confidential and may be stored securely for 10 years at the University of Glasgow. ☐
6. I agree that interviews I might take part in may be recorded. ☐
7. I agree that my data collected during the study, including demographic details, are confidential and may be stored securely for up to 10 years at the University of Glasgow in a form that makes it impossible to identify me. ☐

\_\_\_\_\_  
*Name of Participant*

\_\_\_\_\_  
*Date*

Researchers to fill in below:

\_\_\_\_\_  
*Researcher*

\_\_\_\_\_  
*Date received*

\_\_\_\_\_  
*Signature*

### Appendix 3.7: Demographic and Baseline Questionnaire (Carers)

#### **Demographic and Baseline Questionnaire**

Please complete the questions as fully as you can.

- 1        What is your full name?
  
- 2        What is your email address? (This will not be shared with anyone without your permission and will only be used by the research team).
  
- 3        What is your telephone number? (This will not be shared with anyone without your permission and will only be used by the research team for follow up telephone interviews).
  
- 4        What is the name of your GP? (We would like you to share your registered GP's details with us so that if we are concerned that you or anyone else might be at risk we can contact your GP to let them know this. We will not contact your GP for any other reason).
  
- 5        What is the address of your GP's practice (including postcode)?
  
- 6        What is the telephone number for your GP's practice?
  
- 7        Which best describes your marital status?
  - ☐ Single
  - ☐ Married/Living with partner
  - ☐ In a relationship but living separately
  - ☐ Separated/Divorced
  - ☐ Widowed
  - ☐ Other (please specify)
  
- 8        What is your age?
  
- 9        Do you care for a child/young person with a chronic illness/life limiting illness?
  - ☐ Yes
  - ☐ No
  
- 10       What long-term condition/s does your child/young person suffer from?
  
- 11       Are you the/one of the primary carers for the child/young person?
  - ☐ Yes
  - ☐ No

- 12 Who are you in relation to the young person?
- ☐ Parent
  - ☐ Grandparent
  - ☐ Sibling
  - ☐ Foster carer
  - ☐ Extended family member
  - ☐ Family friend
  - ☐ Other (please specify)
- 13 How long have you been caring for a child/young person with a chronic or life limiting illness?
- 14 How many hours on average do you provide care to the young person per day?
- 15 Do you look after or care for any other children (with or without medical care needs)?
- ☐ Yes
  - ☐ No
- If Yes, how old are the other children?
- 16 Which answer best describes your current working status?
- ☐ Unemployed
  - ☐ Part-time employed
  - ☐ Full time employed
  - ☐ In further education
  - ☐ On maternity leave
  - ☐ Self-employed
  - ☐ On temporary carer's leave
  - ☐ Full time carer (e.g. Not working or receiving carer's allowance)
  - ☐ Other (please specify)
- 17 What is the highest level of education you have completed?
- ☐ No formal qualifications
  - ☐ Standard grade, GCSEs, O-Levels or equivalent
  - ☐ Higher grade, A-Levels or equivalent
  - ☐ HNC, HND, SVQ (Level four to five) or RSA higher diploma or equivalent
  - ☐ Undergraduate degree
  - ☐ Postgraduate degree
  - ☐ Other (please specify)



18 Is English your first language?

- ☐ Yes  
☐ No

If No, what is your first language?

19 What is your ethnic group?

- ☐ White Scottish  
☐ White Irish  
☐ White British  
☐ Any other White background  
☐ Asian Scottish  
☐ Asian British  
☐ Asian Pakistani  
☐ Asian Indian  
☐ Asian Bangladeshi  
☐ Asian Chinese  
☐ Any other Asian background  
☐ Black Scottish  
☐ Black British  
☐ Black Caribbean  
☐ Black African  
☐ Any other Black background  
☐ Any Mixed  
☐ Any other ethnic background  
☐ Prefer not to answer

20 As a carer how supported do you feel by these groups?

	Not supported at all	Supported a little	Supported most of the time	Supported completely	Not applicable or Not available
GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospice staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Carers groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other family members (e.g. siblings, extended family etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends who also care for children with medical needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (Internet Forums, Support Groups).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21 Are you currently seeing anyone for mental health support/treatment?

☐ Yes

☐ No

If Yes, who are you seeing (e.g. counsellor or psychologist) and for what? (E.g. anxiety, low mood etc.)

22 Have you seen anyone for mental health/ support in the past?

☐ Yes

☐ No

If Yes, who (E.g. psychologist counsellor, therapist etc.)

23 Are you taking any medication for your mental health?

☐ Yes

☐ No

If Yes, what medications are you taking? Have they changed in the last month?

24 Do you have a physical disability or any significant medical conditions?

☐ Yes

☐ No

25 Have you been diagnosed with an intellectual/learning disability?

☐ Yes

☐ No

26 Where did you hear about the Study/Programme?

☐ Posters

☐ CHAS Staff

☐ Newsletters

☐ Facebook or Social Media advertisements

☐ Family or friends

☐ 'Living Life to the Full' email updates

☐ Other (please specify)

- 27 Over the last two weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly everyday
Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble falling or staying asleep, or sleeping too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling tired or having little energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor appetite or overeating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling bad about yourself or that you are a failure or have let yourself or your family down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble concentrating on things, such as reading a newspaper or watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving or speaking so slowly that other people could notice? or the opposite –being so fidgety or restless that you have been moving around a lot more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoughts that you would be better off dead or hurting yourself in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 28 Over the last two weeks, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly everyday
Feeling nervous, anxious or on edge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to stop or control worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying too much about different things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble relaxing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being so restless that it is hard to sit still	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming easily annoyed or irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling afraid as if something awful might happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 29 If you checked any of the problems above, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

- ☐ Not difficult at all  
☐ Somewhat difficult  
☐ Very difficult  
☐ Extremely difficult

People's problems sometimes affect their ability to do certain day to day tasks in their lives. To rate your problems. look at each section and determine on the scale provided How much your problem impairs your ability to carry out the activity?  
0 indicates no impairment at all and an 8 indicates very severely impaired.

	Not at all		Slightly		Definitely		Markedly		Very Severely	N/A
	0	1	2	3	4	5	6	7	8	
<b>Work</b> (If you are retired or choose not to have a job for reasons unrelated to your problem, please tick N/A – not applicable)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Home Management</b> Cleaning, tidying, shopping, cooking, looking after the home/children, paying bills etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Social Leisure Activities</b> With other people (E.g. Parties, pubs, outings, entertaining etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Private Leisure Activities</b> Done alone (E.g. reading, gardening, sewing, hobbies, walking etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Family and Relationships</b> Form and maintain close relationships with others including the people that I live with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you for taking the time to complete the questionnaire. A member of the research team will contact you via email to inform you about the next stages of the study.

## Appendix 3.8: Examples of Screen Shots from the Online Course

The first screenshot shows the 'Dashboard' page. At the top, there is a navigation bar with links: 'Family Support', 'My Courses', 'My Library', 'My Resources', and 'Contact Us'. On the right, there are links for 'My Account' and 'Sign Out'. The main header is blue with the text 'Dashboard' and 'Check your progress, take modules and manage your preferences.' Below this is a 'Welcome!' message with a 'Get Started' button. The page is divided into two columns: 'My Courses' and 'My Plans & Reviews'. 'My Courses' lists 'Core Modules' with a list of four items, each with a checkmark and a 'View Course' button. 'My Plans & Reviews' shows 'You don't have any active plans.' and a 'Make a plan' button. Below these is a 'My Reminders' section with a 'Set a reminder' button.

The second screenshot shows the 'Courses' page. The header is green with the text 'Courses' and 'We have a range of courses available, designed to help you tackle many common problems.' Below this are three course cards: 'Core Modules' (purple background, featuring a family icon), 'Optional Modules' (blue background, featuring a checklist icon), and 'You Time Modules' (orange background, featuring a sun icon). Each card has a 'View Course' button. At the bottom, there is a footer with copyright information and links for 'Terms & Conditions', 'Accessibility Policy', 'Privacy Policy', and 'Report A Problem'.

The third screenshot shows the 'Books' page. The header is red with the text 'Books' and 'Discover the power of books to help you learn and change.' Below this is a 'Family Support' section with a 'Family Support' button. The main content area is divided into two columns. The left column features two book covers: 'Why do I feel so bad?' and 'I can't be bothered doing anything'. The right column contains text descriptions for each book, including an introduction and a 'Read it' button.


Family Support My Courses My Library My Resources Contact Us [My Account](#) [Sign Out](#)

## Core Modules

Learn how illness is affecting you & some key changes that can make difference to how you feel.

### Modules


[View all courses](#)



#### Getting ready for change

Step by step work out how illness is affecting you & your family.


[Take this module](#) [Get the worksheets](#)



#### Doing things that make you feel better

Plan activities that make you feel happier.

[Take this module](#) [Get the worksheets](#)




#### Looking at things differently

Family Support My Courses My Library My Resources Contact Us [My Account](#) [Sign Out](#)

## How to offer the support they need

Part of the Core Modules course

[Return to module list](#)



1 / 17

[Make a plan](#) [Set a reminder](#)

### Worksheets

- Planner Sheet.pdf
- Review Sheet.pdf
- Pie Chart.pdf
- Family & friends helpful carer activities.pdf
- Family & friends unhelpful carer activities.pdf

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## Helpful activities by family and friends

- Finding out about depression, for example, by reading the workbooks in this course or other information booklets, getting information from self-help groups or from healthcare practitioners.
- 'Being there' for the person for the long term.
- Being willing to talk and offer support when needed.
- Encouraging asking questions of experts such as health or social workers.
- Encouraging the person to put what they are learning in this course into practice.
- Keeping a positive but realistic outlook that change is possible but will take time.
- Realising there are no quick fixes.
- Using your sense of humour to help you and the person you support to cope.
- Planning time for yourself as well as for others.
- Using effective coping responses, such as relaxation techniques, to deal with your own feelings of tension.
- Looking after yourself.
- Seeing a healthcare practitioner for advice if you yourself are struggling to cope.
- Pacing recovery. Recovering from depression takes time. Even when mood improves, there is period of weeks to months where a person is more vulnerable to relapse. Think about this horizon too when...

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Appendix 3.9: Additional Demographic data (follow-up/ did not complete follow-up)

Demographic characteristics	Total n = 29	Did complete follow up n = 6 (20.7%)	Did not Complete follow up n = 23 (79.3%)
<b>Age</b>			
25 - 34	5 (17.2)	2 (33.3)	3 (13)
35 - 44	13 (44.8)	2 (33.3)	11 (47.8)
45 - 54	10 (34.5)	1 (16.7)	9 (39.1)
55 – 64	1 (3)	1 (16.7)	0 (0)
<b>Gender</b>			
Male	1 (3.4)	0 (0)	1 (4.3)
Female	28 (96.6)	6 (100)	22 (95.7)
<b>Marital Status</b>			
Single	2 (6.9)	0 (0)	2 (8.7)
Married/Living with partner	19 (65.5)	4 (66.7)	15 (65.2)
Separated/Divorced	8 (27.6)	2 (33.3)	6 (26.1)
<b>Working Status</b>			
Full time employed	5 (17.2)	1 (16.7)	4 (17.4)
Part-time employed	9 (31)	1 (16.7)	8 (34.8)
Self-employed	1 (3.4)	0 (0)	1 (4.3)
Long-term sick leave	1 (3.4)	1 (16.7)	0 (0)
Full time carer	13 (44.8)	3 (50)	10 (43.6)
<b>Own physical disability</b>			
Yes	7 (24.1)	0 (0)	7(30.4)
No	22 (75.9)	6 (100)	16 (69.6)
<b>Receiving support for Mental Health</b>			
Yes	11 (37.9)	2 (33.3)	9(39.1)
No	18 (62.1)	4 (66.7)	14 (60.9)
<b>Past support for Mental Health</b>			
Yes	21 (72.4)	5 (83.3)	16 (69.6)
No	8 (27.6)	1 (16.7)	7 (30.4)
<b>Current medication for Mental Health</b>			
Yes	14 (48.3)	2 (33.3)	12 (52.2)
No	15 (51.7)	4 (66.7)	11 (47.8)
<b>Average hours caring each day</b>			
0 – 6	1 (3.4)	0 (0)	1 (4.3)
7 – 12	6 (20.7)	1 (16.7)	5 (21.7)
13 – 18	7 (24.1)	4 (66.7)	3 (13)
19 – 24	13 (44.8)	1 (16.7)	12 (52.2)
No information	2 (6.9)	0 (0)	2 (8.6)
<b>Other children to care for</b>			
Yes	19 (65.5)	4 (66.7)	15 (65.2)
No	10 (34.5)	2 (33.3)	8 (34.8)

Appendix 3.10: Additional Data: Median baseline scores on secondary outcome measures (follow-up/ did not complete follow-up)

	<b>Total Sample n=29</b>	<b>Did complete follow up n = 6</b>	<b>Did not Complete follow up n = 23</b>
	<b>Median (IQR)</b>	<b>Median (IQR)</b>	<b>Median (IQR)</b>
GAD7	9 (6 - 13)	10 (5.5 – 14.5)	9 (6 – 13)
PHQ9	12 (7 – 16)	7 (6.25 – 15.25)	13 (8 – 15)
WASAS	23 (12 – 27)	19 (15.25 – 22.75)	25 (11 – 29)



## Appendix 3.11: Focus Group Interview Schedule

### **Focus Group Interview Schedule** **Staff Perspectives on Carer Stress and Support Needs**

*I'm going to ask you some questions about your thoughts and opinions about the online course that was just demonstrated and discussed. Please do not hesitate to be honest. This will help us to better tailor the course to meet the needs of parents and carers.*

#### **About the website:**

- What did you think about the online life skills course/worksheets?
- Anything you like/don't like?
- Do you think it would be suitable for parents of children with LLI?
- Is it accessible?
- From your experience would parents use this package?
- What kind of support could be offered to help people get the most out of it?
- Could this support be delivered by hospice staff, third sector, nurses?
- What could be changed to make it more acceptable?
- Email or telephone support could be made available for parents completing the course. What do you think about the offer of something like this?

## Appendix 3.12: Hospice Staff Questionnaire

### Hospice Staff Questionnaire: Perspectives on Carer stress and Support

#### 1) Tell us about yourself:

- a). Job title/Role: \_\_\_\_\_ Age (years): \_\_\_\_
- b). Gender (circle): F / M / Other      Years working in palliative/end of life care: \_\_\_\_
- c). What is your professional background: Nurse ☐      Doctor ☐      O.T. ☐      Physiotherapist ☐  
Dietician ☐      Counsellor ☐      None ☐      Other: .....
- d). Are you a permanent member of staff with CHAS?      Yes ☐ No ☐
- e). Does your role involve providing emotional support/advice to parents?      Yes ☐ No ☐
- f). Does your role involve providing practical support to parents?      Yes ☐ No ☐
- g). Have you had any formal training in mental/psychological issues e.g. RMN, or significant mental health course > 1 week?      Yes ☐  
No ☐
- h). How confident are you in talking about difficult emotional issues with parents?  
1= Not at all, 6 = Very confident      **1 2 3 4 5 6**
- i). How confident are you in talking about practical issues with parents?  
1= Not at all, 6 = Very confident      **1 2 3 4 5 6**

#### 2) We are looking to have content on the site that is useful. Please help us identify content areas we should include:

What are the most common difficulties or stressors that parents report that cause them distress?

What sources of support do parents report to be beneficial?

What issues do parents find it difficult to ask about?

What practical problems do parents often face?

What annoys parents?

**3) Finally, please indicate whether the following should be included in the online package:**

	Yes	No	Comments/suggestions of what would be useful
Looking after and communicating with siblings			
Balancing family demands			
Talking to your child about illness, treatment and procedures			
Managing anxiety			
Tackling low mood			
Relationship conflicts with partners			
Getting/developing social support			
Balancing family demands			
Communicating with health staff			
Financial burden			
Maintaining a 'normal' family life			
Disciplining your child			
Educating /communicating with family/friends			
Self-Care – support plans, groups			
Talking through emotions with your child			
Responding to Behavioural difficulties			

**We really appreciate your participation in this survey. Thank you!**

**Contact details:**

**Lauren Manuel email: [l.manuel.1@research.gla.ac.uk](mailto:l.manuel.1@research.gla.ac.uk)**

**Chris Williams email: [chris.williams@glasgow.ac.uk](mailto:chris.williams@glasgow.ac.uk)**

## Appendix 3.13: Copy of Ethics Approval Letter



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

14<sup>th</sup> December 2016

Dear Professor Williams

**MVLS College Ethics Committee**

**Project Title:** Supporting carers of young people with life limiting illnesses with online cognitive behavioural therapy-based support packages

**Project No:** 200160046

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: 31 July 2017
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:  
([http://www.gla.ac.uk/media/media\\_227599\\_en.pdf](http://www.gla.ac.uk/media/media_227599_en.pdf))
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

A handwritten signature in black ink that reads 'Dorothy McKeegan'.

Dr Dorothy McKeegan  
College Ethics Officer

Dr Dorothy McKeegan

Senior Lecturer

R303 Level 3  
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## Appendix 3.14: Follow-up Questionnaire (Carers)

### **Living Life to the Full for Parents and Carers- Online Support Course**

#### **Follow-Up Questionnaire (completed online)**

#### **Information about the Follow-up Questionnaire**

*Thank you very much for taking the time to participate in trailing the online course for parents and carers of children with life limiting and chronic conditions. We hope you found it useful.*

*As part of the evaluation of the online course we are asking all participants to complete a brief follow -up questionnaire.*

*The following questionnaire includes some questions about your mood (the same ones that you completed before starting the online course) and some questions about your experience of the online course.*

*Responses from this questionnaire will help the research team to evaluate the potential effectiveness of the online course and identify ways in which it can be improved to better suit the needs of future parents and carers.*

*All responses from participants are invaluable to the completion of the research trial. Please answer as many of the questions as you can.*

*All the information collected will be stored securely according to the Data Protection Act 1998 and will be kept entirely confidential and will not be disclosed to anyone outside the immediate research team without your permission.*

*Please contact us if there is anything that is not clear or if you would like more information.*

Contact details for research team:

Lauren Manuel  
Email: l.manuel.1@research.gla.ac.uk

Mental Health and Wellbeing  
Administration Building  
Gartnavel Royal Hospital,  
1055 Great Western Road,  
Glasgow,  
G12 0XH

*Thank you for taking the time to read this and for participating in the study!*

1. What is your full name? (this will only be used for contacting you)
2. What is your e-mail address? (This will not be shared with anyone without your permission and will only be used by the research team).
3. What is your telephone number? (This will not be shared with anyone without your permission and will only be used by the research team for follow up telephone interviews).
4. Since beginning the online course has anything changed with the care that you have been personally receiving? (e.g. changing medications or starting individual therapy with a mental health professional).
  - Yes- Please specify in the comments box below
  - No
5. Since starting the online course have you used any of the following supports for your mood?

GP	Yes	No
Hospice Staff	Yes	No
Reading Self Help books	Yes	No
Telephone Support Lines	Yes	No
Carers Groups/Speaking with other carers	Yes	No
Psychological or Counselling services	Yes	No
Psychological Services	Yes	No
Other (e.g. Internet forums, Support Groups)	Yes	No

**The next set of questions are about your mood. It is suggested that you do not spend too long thinking about these questions and go with your first response.**

6. Over the **last two weeks**, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things				
Feeling down, depressed, or hopeless				

Trouble falling or staying asleep, or sleeping too much				
Feeling tired or having little energy				
Poor appetite or overeating				
Feeling bad about yourself-or that you are a failure or have let yourself or your family down				
Trouble concentrating on things, such as reading the newspaper or watching television				
Moving or speaking so slowly that other people could notice? Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual				
Thoughts that you would be better off dead or hurting yourself in some way				

7. Over the **last two weeks**, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge				
Not being able to stop or control worry				
Worrying too much about different things				
Trouble relaxing				
Being so restless that it is hard to sit still				
Becoming easily annoyed or irritable				
Feeling afraid as if something awful might happen				

8. People's problems sometimes affect their ability to do day to day tasks in their lives. Using the scale below please look at each section and rate how much your problem(s) impair your ability to carry out each activity.

Not at all 0	1	Slightly 2	3	Definitely 4	5	Markedly 6	7	Severely 8
--------------------	---	---------------	---	-----------------	---	---------------	---	---------------

	0	1	2	3	4	5	6	7	8
My <b>ability to work</b> is impaired									
My <b>home management</b> (cleaning, tidying, shopping, cooking, looking after the children, paying bills) is impaired									
My <b>social leisure activities</b> (with other people e.g. outings, visits, dating, home entertainment) are impaired									
My <b>private leisure activities</b> (done alone, such as reading, gardening, walking, sewing) are impaired									
My ability to <b>form and maintain close relationships</b> with others, including those I live with, is impaired.									

9. The next set of questions are about your experience of using the online support course

1. How would you rate the quality of service you have received?	1 Poor	2 Fair	3 Good	4 Excellent
2. Did you get the kind of service you wanted?	1 No, definitely not	2 No, not really	3 Yes, generally	4 Yes, Definitely
3. To what extent has our program met your needs?	1 None of my needs have been met	2 Only a few of my needs have been met	3 Most of my needs have been met	4 Almost all of my needs have been met



4. If a friend were in need of similar help, would you recommend our program to him or her?	1 No, definitely not	2 No, I don't think so	3 Yes, I think so	4 Yes, definitely
5. How satisfied are you with the amount of help you have received?	1 Indifferent or mildly dissatisfied	2 Quite dissatisfied	3 Mostly satisfied	4 Very satisfied
6. Have the services you received helped you to deal more effectively with your problems?	1 No, they seemed to make things worse	2 No, they really didn't help	3 Yes, they helped	4 Yes, they helped a great deal
7. In an overall, general sense, how satisfied are you with the service you have received?	1 Quite dissatisfied	2 Indifferent or mildly dissatisfied	3 Mostly satisfied	4 Very satisfied
8. If you were to seek help again, would you come back to our program?	1 No, definitely not	2 No, I don't think so	3 Yes, I think so	4 Yes, definitely

10. What are your thoughts or feelings about the course being offered online rather than in a face to face situation?

11. What was your general impression of the online course (e.g. things you liked/didn't like)?

12. What did you think about the content included in the modules on the the online course?

13. Are there any other topics that you would add or take away from the online course?

14. What were your thought on the weekly email support that was offered with the online course?

15. What did you think about the information provided about the research (e.g. was there enough information provided? what was your experience of the questionnaires you completed?, etc.)

16. Would you like to leave any other comments about the research or online course?

**Thank you for taking the time to complete the follow-up questionnaire. A member of the research team will contact you via email to inform you about the final stages of the study.**

### Appendix 3.15: Standardized email template used to guide email support

*Hi, my name is Harriet Bowyer, I am a Trainee Clinical Psychologist based at the University of Glasgow. My role is to support and encourage you while you work through the online course. You may find at points some tasks difficult or that you lose motivation so I am here to help.*

*Have you managed to register and log on to the website?*

*How have you been doing? Did you find the first module helpful?*

*Please do not feel obliged to complete all of the modules or in any particular order. Pick and choose the ones right for you. Some people find it beneficial to try and aim to look at one module a week to keep up momentum and improve how you feel.*

*The Planner and Review sheets can be extremely helpful to support you in making a clear plan at the end of each module for what you would like to try and achieve in the coming week. There are some instructions on how to use them in the Welcome module.*

*Please do use me as a resource to help you get the most out of the course. I am here to help and all correspondence will be kept confidential within the research project, unless I am seriously concerned about your wellbeing.*

*I look forward to hearing from you.*

*Kind regards,  
Harriet Bowyer  
Trainee Clinical Psychologist*

**Supporting Carers of Young People with Life Limiting Illnesses with Online  
Cognitive Behavioural Therapy Support Packages**

**ABSTRACT**

**Background:**

Life limiting illnesses (LLI) in young people are conditions for which there is no reasonable hope or cure and from the young person will die. LLI can also include those for which curative treatment are feasible but have potential to fail, such as cancer (Fraser et al., 2011). Carers of young people with LLI can encounter a range of difficulties including depression, anxiety and marital distress. Carers can also struggle with communicating with clinical staff involved in their child's care and in communicating with their child about treatment pathways. In addition carers can struggle to co-ordinate the range of hospital appointments required for their child, leaving little time for self-care or to attend sessions for self-support. Despite these difficulties there is very little research into the provision of support packages for carers of young people with LLI, which may be accessible and helpful.

**Aims:** to investigate themes and areas which cause carers significant difficulty and tailor an existing online support package to address carer needs. The research aims to evaluate the feasibility and acceptability of the tailored online Cognitive Behavioural Therapy (CBT) support package.

**Methods:** An existing life skills course ([www.lltff.com](http://www.lltff.com)) will be modified to introduce elements aimed at carers of young people with LLI.

- i. A short staff questionnaire of professionals based at a children's hospice in Balloch will explore attitudes towards carer support and recommendations for possible content for the tailored online package.
- ii. A feasibility trial will then test the acceptability of the package, completion rates, attrition, recruitment for and delivery of the online course, and gather questionnaires from the target group (parents/carers). Pre and post intervention measures of carer anxiety, distress and depression will be gathered to estimate the potential clinical effect of the intervention. Purposive qualitative interviews/focus groups will be conducted with carers who have used the online package to explore acceptability and establish areas where the package could be modified or extended, and consider how it is best supported. Thematic analysis will be used to analyse interview data.

**Applications:** The trial will reduce uncertainties regarding the delivery of a future substantive randomized controlled study in a hospice/community. If found to be acceptable/effective the online support package could be made available to families across Scotland.

## **1. Introduction**

Carers of young people with Life Limiting Illnesses (LLI) face a number of challenges in addition to supporting their child (Lewis and Prescott, 2006). These can include how to inform children of the implications of illness and treatment, how to liaise with medical staff and difficulties with managing their own self-care. Carers are known to have high rates of depression, anxiety and marital distress (Dahlquist et al, 1993). It has been found that parents' appraisal of their own ability to cope significantly predicts distress (Sloper et al. 2000). This indicates that cognitive behavioural support packages may be acceptable and helpful to carers of young people with LLI.

In wider mental health services computerized Cognitive Behavioural Therapy (CBT) is a recommended treatment option for depression and anxiety disorders (NICE, 2006). This mode of treatment provides a reliable structure for delivery and promotes a greater capacity for support in services.

In some chronic disorders (e.g. anorexia), specific packages for parents have shown to improve carer mood, reduce anxiety, build confidence and reduce expressed emotion. Modes of delivery for carer based support packages include online (Grover et al., 2011), and DVD supports (Sepulveda et al., 2008). There is also a growing literature of book-based treatments for carers (McCann et al. 2012).

To date our scoping reviews have identified little research evaluating support packages specifically tailored for carers of young people with LLI.

Support for carers can be obtained from medical staff and community resources, with carers reporting great benefits from hospice support (Davies et al. 2004). Unfortunately, due to geographical/time limitations, many are unable to access support offered at the two Scottish hospices located in Glasgow (Robin House, est. 2005) and Edinburgh (Rachel

House, est. 1996). Hospices are responding to these challenges by offering phone and home-based services. There is, however, still an ongoing demand. It is possible that the provision of online support for carers may assist in meeting this demand. Therefore providing potential scope for the development of a tailored, low intensity CBT-base intervention for carers of young people with LLI.

## **2. Aims**

### **2.1 Study 1: Short staff questionnaire**

To distribute a staff questionnaire, which will inform the content and modification of the existing online package (Living Life to the Full) to better engage carers.

### **2.2 Study 2: Feasibility study of the online package and qualitative focus groups.**

To evaluate the feasibility, acceptability, take-up, attrition and completion of a tailored online CBT package, which aims to provide support for carers/parents of young people with LLI.

Interviews/focus groups of carers who have used the online course, including participants who have a) dropped-out, and b) completed the course will aim to explore attitudes concerning:

- Content for supporting the young person.
- Content for supporting siblings.
- Communicating with professionals.
- Self-care (specifically depression and anxiety).
- Thoughts concerning how participants would like to use the online resource, and whether they would value support from a practitioner/hospice worker or not. If support is required, how would it be delivered?

## **3. Hypotheses**

1). It will be possible to identify recommended topics by short staff survey of Robin House staff, including community based staff.

2). It will be possible to recruit 20-30 people into the feasibility study, and 10-12+ people into focus group interviews concerning the course (leading to saturation).

- 3). It will be possible to gather evaluation questionnaires online or by post from participants.
- 4). Carers of young people with LLI will show a significant reduction in carer depression and anxiety following completion of online support based package.
- 5). It will be possible to clarify and reduce uncertainty concerning key components of the study process, including creating a power calculation to inform sample size for a future substantive study.

## **4. Plan of Investigation**

### **4.1 Participants**

Participants will include parent(s) or carer(s) of young people with LLI who are receiving/have received treatment/support at the Children's Hospice, Robin House, in Balloch and staff/professionals who support young people and their carers. We will also include the option to recruit directly from the community.

### **4.2 Recruitment Procedures:**

#### **4.2.1 Study 1: Staff Questionnaire**

A 45 minute presentation about the research project will be delivered to staff at Robin House and staff based in the community. The presentation will provide information about the research, inform staff how they can aid the research (e.g. facilitating recruitment), and disseminate for collection and completion a short questionnaire exploring topics staff would recommend for incorporation into the online package. Questionnaires will be sent by post or online (survey monkey) to staff who wish to participate but are unable to attend. Approval will be sought from Robin House management for the above process.

#### **4.2.2 Study 2: Feasibility study**

Opportunities to participate in research will be advertised through posters/newsletters at Robin House, through hospice staff, and more widely in communities via free sheets (e.g. Metro), and charity websites (e.g. CHAS). Potential participants may also be contacted directly by the researchers if carers have given consent to staff at Robin House.

If carers are interested in research participation they will be directed by the posters/adverts/staff at Robin House to visit an online study recruitment website. The website will include information about the research. It will provide access to Participant Information sheets and contact details for the research team who will be available to answer further questions.

If carers would like to participate in the research, they will be invited to complete an online series of questions, which will compare their suitability for participation against the given inclusion/exclusion criteria. If criteria are met participants will be able to give fully informed consent and access to baseline measures for completion via the website.

### **4.3 Inclusion and Exclusion Criteria**

Inclusion criteria:

- Parent/carer of a young person with a LLI, being supported by Robin House Hospice.
- Willing to consent to the appropriate study (1 or 2).

Exclusion:

- Unwilling to consent.
- Cannot Speak English.
- No access to the internet or a computer.

### **4.4 Measures**

Participants will be given a range of self-report measures at baseline (pre intervention), post intervention and at follow-up (12 weeks post intervention).

4.4.3 Patient Health Questionnaire 9 (PHQ-9) is a multiple choice, self-report measure for the screening and monitoring of the severity of depression. Total scores can range between 0 and 27. Scores of 5, 10, 15, and 20 represent cut off points for mild, moderate, moderately severe and severe depression, respectively.

4.4.4 Generalized Anxiety Disorder 7 (GAD-7) is a self-report questionnaire used in the screening and measuring of Generalised anxiety. It consist of 7 items.



Scores of 5, 10, and 15 are taken as the cut off points for mild, moderate, and severe anxiety, respectively.

4.4.5 Work and Social Adjustment Scale (WSAS) is a multiple choice, 5 item, self-report measure, which assess the impact of mental health difficulties on functioning in terms of work, home management, social leisure, private leisure and personal or family relationships.

4.4.6 Client Satisfaction Scale (CSQ-8) is an 8-item self-report measure which is designed to measure client satisfaction with services. Scores range from 8 to 32, with higher scores indicating greater levels of satisfaction.

## **5. Design**

### **5.1 Study 1: Staff Questionnaire**

A short paper-based questionnaire using Likert style questions and open text box responses will:

- i. Consider how such as package could be delivered and supported by staff.
- ii. identify content topics felt to be of value to parents/carers for incorporation into the online carer support package (Main research project).

### **5.2 Study 2: Feasibility Study**

5.2.1 The feasibility study will be a repeated measures design with a sample of 20 to 30 participants and will evaluate:

- The ability to recruit and retain carers in a research study, and to gather baseline and follow-up data.
- The ability to introduce the online package and to record participant use of the course resources (logins, time logged in, modules started/finished).
- Participant attitudes/feedback and satisfaction regarding the treatment.
- An estimate of the effect of the intervention on key measures such as mood, anxiety, social function, perceived ability to support their child and satisfaction.

Participants who meet inclusion/exclusion criteria will be invited to complete a range of online modules. The package will consist of several 'Core' modules and optional modules, which participants can choose depending on their needs.

Dependent on data collected in study 1, participants might also be provided with telephone or email support when completing the online support package.

A time-frame will be set for completion of the online course and participants will be encouraged to attempt to complete one module per week.

At post intervention and follow up (12 weeks) participants will be asked to repeat the series of outcome measures initially completed at pre-intervention. Participants will also be invited to participate in an interview of treatment acceptability (qualitative interview).

#### 5.2.2 Qualitative interview assessing acceptability:

1. Carers will be offered the option of one to one face-to-face interviews, interviews by telephone or as part of a small focus group.
2. Ideally 2-3 focus groups of 3-6 carers will be conducted. A topic guide of semi-structured questions will be generated to provide a structure for the interviews.

With the consent of participants, interviews will be digitally recorded, transcribed and analysed. The researcher will take notes of any nonverbal information. Interviews will last between 45 and 60 minutes and will be held on a single occasion. Sufficient interviews will be conducted to achieve saturation, where no new concepts/key ideas are identified.

### **6. Data analysis**

The feasibility study will describe take-up and drop-out figures. Participants will be emailed on up to two occasions with links to follow-up questionnaires or sent the same questionnaires by post. Up to two completed reminder phone calls may be offered.

We do not expect to be able to fully analyse quantitative data, but will describe the ability to gather data, and estimate changes in mean outcome measures from baseline to end of package use (6 weeks), and 6 weeks after that (12 weeks).

The study will help inform the most appropriate primary outcome (via the focus group and staff questionnaires). We expect provisionally this will be carer depression (PHQ9). From

this a sample size calculation will be performed on the PHQ9 to establish the sample size required for a future substantive study.

Qualitative data from the focus groups (assessment of acceptability) will be analysed using Thematic Analysis (TA). TA has been selected due to the emphasis it places on pinpointing, examining and identifying 'themes' within the data. Thematic analysis is performed through a six phase coding process, which aim to create established patterns (Braun and Clarke, 2006). TA has been considered above Interpretative Phenomenological analysis (IPA) for the the interviews aim to identify key themes which may arise around the acceptability of the package.

## **7. Justification of Sample Size**

Formal power calculations are not usually undertaken when conducting feasibility studies. What is required is a sufficient sample size to calculate the critical parameters relating to the feasibility outcomes of the trial (e.g. attrition, completion rates, recruitment) (Arian et al. 2010). Following this guidance the sample size of 30 will be recruited (Billingham et al. 2013).

## **8. Setting and Equipment**

Home visits will not be conducted during the research. All interviews will either be held within the clinical setting of Robin House or via a telephone (including participants recruited from the community).

The primary researcher will require access to transcription kits, an encrypted laptop, audio recording and telephone recording devices.

## **9. Health and Safety Issues**

The research will not record a risk assessment or make any diagnoses of mental health problems. However, if at any stage concern is raised regarding the health/safety of participants/others (e.g. the child supported or siblings), we will encourage participants to seek help from Robin House and/or their GP. Information sheets with appropriate support contact information will also be provided to participants as well as being available as an "Urgent Help" tab on the website.

### **9.1 Researcher safety issues**

The recruitment sample are not usually associated with dangerous or unpredictable behaviour. Interviews conducted during the research will be either on an individual basis or within small groups. This is similar to procedures which are common within the work remit of clinical psychologists. Some topics discussed during interviews may produce some distress to the researcher, however this will not be significantly higher than average working situations. Supervision will be regularly attended by the primary researcher to discuss distress, which might affect fitness to work. All research procedures will be completed in a clinical/academic setting, where additional support will be available from clinical/academic staff.

### **9.2 Participant safety issues**

Informed consent will be recorded from all participants completing any part of the research. The opportunity to discontinue participation without any repercussions will be clearly outlined during the opt-in stage and at the beginning of the qualitative interviews. Any questions regarding confidentiality will be answered.

If participants disclose information, which would be indicative of risk to themselves or others action is taken which is in line with NHS, BPS and Robin House Confidentiality guidance.

Engagement in focus groups/interviews or the online intervention may potentially cause distress to participants due to the possible emotive nature of the discussion. Participants will be given space to leave interviews if they wish. All interviews will be held within a private clinical setting. Distress is not anticipated to be higher for the participants than that encountered during usual engagement with clinical support staff. It might be that carers find the setting mutually supportive for validating their caring experience.

## **10. Ethical issues**

Ethical approval will be sought from The University of Glasgow IHW ethics committee. NHS ethical approval will not be sought as participants will not include NHS patients. Approval for the research will also be obtained from the management team at Robin House. Informed consent will be obtained from all participants. Participants will also

receive emailed versions of information sheets outlining limitations of confidentiality, data storage and the right to withdraw.

Data will be handled and stored in accordance with the Data protection Act (1998), the Freedom of Information Act (2000). All participant identifiers will be removed. A separate password protected Excel file will be held on University computers (server) linking patient identifiers to the patient ID numbers. Any recorded material will be stored on an encrypted laptop and will be destroyed from recording devices once transcribed.

### **11. Financial issues**

Equipment costs will amount to one digital recording kit, telephone recording equipment, posting/printings costs and a transcribing kit. Equipment will be borrowed from the University of Glasgow. Travel costs to Robin House, Balloch will initially be sought from NHS Education for Scotland.

### **12. Timetable**

- 1). Staff interview: (June-July 2016-02-01).
- 2). Course module creation and update (July-August 2016).
- 3). Feasibility study and carer interviews (Recruitment Sept-October 2016).
- 4). Follow-up September 2016- January 2017.
- 5). Write-up and evaluations February and March 2017.

### **13. Practical Applications and Dissemination**

Anonymised research results will be presented as a poster/oral presentation at research conferences, as well as in local newsletters from the Hospice. The intention is the course will be available online free of charge at [www.lltff.com](http://www.lltff.com) after future substantive research is completed.

### **14. References**

Arañ, M., Campbell, M. J., Cooper, C. L., & Lancaster, G. A. (2010). What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC medical research methodology*, 10(1), 67.

Billingham, S. A., Whitehead, A. L., & Julious, S. A. (2013). An audit of sample sizes for pilot and feasibility trials being undertaken in the United Kingdom registered in the United Kingdom Clinical Research Network database. *BMC medical research methodology*, 13(1), 104.

Braun, Virginia; Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3 (2): 83.

Dahlquist, L. M., Czyzewski, D. I., Copeland, K. G., Jones, C. L., Taub, E., & Vaughan, J. K. (1993). Parents of children newly diagnosed with cancer: anxiety, coping, and marital distress. *Journal of pediatric psychology*, 18(3), 365-376.

Davies, B., Steele, R., Collins, J. B., Cook, K., & Smith, S. (2004). The impact on families of respite care in a children's hospice program. *Journal of palliative care*, 20(4), 277.

Fraser, L. K., Miller, M., Aldridge, J., McKinney, P. A., Parslow, R. C., & Hain, R. (2011). Final Report for Children's Hospice UK.

Grover M, Naumann U, Mohammad-Dar L, Glennon D, Ringwood S, Eisler I, Williams C, Treasure J, Schmidt U. (2011). A randomized controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa. *Psychol Med.*, 41(12):2581-91.

McCann, T. V., Lubman, D. I., Cotton, S. M., Murphy, B., Crisp, K., Catania, L., & Gleeson, J. F. (2012). A randomized controlled trial of bibliotherapy for carers of young people with first-episode psychosis. *Schizophrenia bulletin*, sbs121.7

National Institute for Health and Care Excellence (2006) Technology appraisal guidance (TA97). <https://www.nice.org.uk/guidance/ta97>

Parliament, B. (1998). Data protection act of 1998.

Parliament, B. (2000). Freedom of Information act of 2000.

Sepulveda, A. R., Lopez, C., Macdonald, P., & Treasure, J. (2008). Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder. *International Journal of Eating Disorders*, 41(4), 318-325.

Sloper, P. (2000). Predictors of distress in parents of children with cancer: A prospective study. *Journal of pediatric psychology*, 25(2), 79-91.

Spitzer, R. L., Kroenke, K., Williams, J. B. W. & Lowe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. *Arch. Intern. Med.*, 166, 1093-1097

## **15. Appendix**

### **15.1 Plain English Summary**

**Title:** Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy Support Packages.

**Background:** Carers of young people with Life Limiting Illnesses (LLI) face a number of challenges in addition to caring for their child. LLI are conditions for which there is no reasonable hope or cure and from which the person will die. Challenges of caring can include struggling to communicate with staff, difficulties communicating treatment choices to children and co-ordinating appointments. Carers can also experience higher rates of depression, anxiety and marital distress (Dahlquist et al, 1993). These challenges leave limited time for self-care. Despite these difficulties there is little research into support packages for carers of people with LLI. Carers have reported benefits from hospice support (Davies et al. 2004). However unfortunately, due to geographical limitations, many cannot access support offered at Scottish hospices. This research will therefore explore the feasibility/acceptability of a more accessible, online support-based intervention tailored for carers of young people with LLI.

**Aims:** To use staff questionnaires to promote understanding of challenges for carers of young people with LLI.

To test the feasibility, acceptability, take-up, drop-out and completion of a tailored online support package for carers of young people with LLI.

**Methods:** Participants will include carers/parents of children with LLI and staff that assist them. Participants will be recruited from Robin House Children's Hospice and community advertisements. Interested participants will be invited to access a website, which will provide further details about the research. Fully informed consent will be obtained on the website..

A short staff questionnaire will be distributed to staff at Robin House to explore the attitudes towards carer support and recommendations for an online support package.

A feasibility trial of the tailored online support package for carers will be conducted. Pre and post-intervention self-report measures of anxiety and depression will be administered online to estimate the clinical effect of the intervention. Focus groups will then be conducted with carers who have used the package to assess the acceptability of the treatment. Data collected during the focus groups/feasibility trial will inform the future development of the support package.

**Ethical Issues:** Information regarding confidentiality will be provided. If concern is raised regarding health/safety of participants/others procedures will be followed. Participants will also be provided with appropriate support contacts. The right to withdraw will be clearly outlined throughout the research process.

**Study Impacts:** Findings from qualitative interviews and the feasibility trial will reduce uncertainties about the delivery of a future substantive randomized controlled trial. If found to be acceptable/effective the online support package could be made freely available online.

#### **References:**

Dahlquist, L. M., Czyzewski, D. I., Copeland, K. G., Jones, C. L., Taub, E., & Vaughan, J. K. (1993). Parents of children newly diagnosed with cancer: anxiety, coping, and marital distress. *Journal of pediatric psychology*, 18(3), 365-376.

Davies, B., Steele, R., Collins, J. B., Cook, K., & Smith, S. (2004). The impact on families of respite care in a children's hospice program. *Journal of palliative care*, 20(4), 277.

#### **15.2 Health and Safety for Researchers Form**

##### **WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW DOCTORATE IN CLINICAL PSYCHOLOGY**

##### **HEALTH AND SAFETY FOR RESEARCHERS**

1. Title of Project	Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy Support Packages
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2. Trainee	
3. University Supervisor	Prof. Chris Williams
4. Other Supervisor(s)	N/A
5. Local Lead Clinician	Dr Paul Boutcher (CHAS)
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	<p>Carers/parents of young people with Life limiting illnesses</p> <p>Professional staff involved in the care of young people with life limiting illnesses</p>
7. Procedures to be applied (eg, questionnaire, interview, etc)	<p>Staff questionnaire (explore opinions about online package and topics for content)</p> <p>Feasibility study – carers will be invited to complete an online support based package tailored for carers.</p> <p>Pre, Post and Follow up outcome measures will be completed by participants.</p> <p>Focus groups or telephone interviews will be used to assess and evaluate the online package's acceptability.</p>
8. Setting (where will procedures be carried out?)	<p>All interviews/focus groups will be held either via telephone or in Robin House Children's Hospice.</p> <p>The online support package and outcome measures will be completed by participants independently with the use of a computer, usually within their own home.</p>
i) Details of all settings	
ii) Are home visits involved	No

<p>9. Potential Risk Factors Considered (for researcher and participant safety):</p> <ul style="list-style-type: none"> <li>i) Participants</li> <li>ii) Procedures</li> <li>iii) Settings</li> </ul>	<p>Participants: Participants will include parents/carers and staff who are involved in the care of a young person with a life limiting condition. The participants are not usually associated with dangerous or unpredictable behaviour, however they may be more vulnerable than the general population to depression and anxiety.</p> <p>Procedures:</p> <p>Interviews conducted during the research will be either on an individual basis or within small groups. This is similar to procedures which are common within the work remit of clinical psychologists. Some topics that may be discussed during interviews may produce some distress to the researcher, however this will not be significantly higher than what is encountered within average working situations.</p> <p>There is a possibility that engagement in focus groups/ interviews or the online intervention may cause distress to participants due to emotive nature of topics.</p> <p>Settings: No issues identified by the research setting, however Robin House procedures for minimizing risk will be adhered to.</p>
<p>10. 10. Actions to minimise risk (refer to 9)</p> <ul style="list-style-type: none"> <li>i) Participants</li> <li>ii) Procedures</li> <li>iii) Settings</li> </ul>	<p>Procedures:</p> <p>All participants will be fully informed of the risks involved in the research before consenting.</p> <p>Participants will be given space to leave interviews if they feel they require it. All interview will be held within a private clinical setting. Distress is not anticipated to be higher than would be expected for the participant compared to their usual</p>

	<p>engagement with clinical support staff.</p> <p>If at any stage concern is raised regarding the health and safety of participants or others (e.g. the child supported or their siblings), we will ask participants to seek help from Robin House and/or their GP, and also provide an information sheet with appropriate numbers and support contact information – this information will also be available as an “Urgent Help” tab on the support package website.</p> <p>Contact information for a member of the research team will also be provided for participants.</p> <p>Supervision will be regularly attended by the primary researcher to discuss any significant distress, which might affect fitness to work.</p> <p>Settings: All research procedures will be completed by the researcher in a clinical or academic setting where additional support will be available if required from clinical or academic staff. Robin House procedures for minimizing risk will also be adhered to.</p>
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### 15.3 Equipment Form

#### **RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES**

**Project Title: Supporting Carers of Young People with Life Limiting Illnesses with Online Cognitive Behavioural Therapy-based Support Packages**

**Year of Course**2016      **Intake Year** 2014

Please refer to latest stationary costs list (available from student support team)

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary	Envelopes (1 box 250)	Subtotal: £ 9.01
Postage	Freepost Letters (60)	Subtotal: £37.20
Photocopying and Laser Printing	Printing approx. 500	Subtotal: £25
Equipment and Software	Transcribing equipment Telephone recording device Encrypted laptop Recording device	Borrowed from university
Measures	All freely available	Subtotal: £0
Miscellaneous		Subtotal:
<b>Total</b>		£71.21

Trainee Signature..... Date.....

Supervisor's Signature ..... Date .....

## **Chapter 4: Advanced Clinical Practice I Reflective Critical Account Abstract**

### **Supervision: A Safe Base for Training in Clinical Psychology**

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Word Count (including references): 131

## **ABSTRACT**

In this account I reflect on my experiences of clinical supervision and its influence on my personal and professional development. This reflective account is loosely structured on Gibb's reflective Cycle (1988) and the Integrated Developmental Model of Supervision proposed by Stoltenberg et al. (1998). This reflection charts my different learning experiences during supervision including examples of how they have influenced my skills in using formulation, my self-awareness and professional confidence. I also reflect on the strategies used in supervision and my thoughts and feeling in response to these. Finally, this account considers how my experiences of supervision may influence my approach to delivering supervision in the future.

## **REFERENCES**

Stoltenberg, C.D., McNeill, B. & Delworth, U. (1998) IDM Supervision: An Integrated Developmental Model of Supervising Counselors and Therapists. San Francisco: Jossey-Bass.

## **Chapter 5: Advanced Clinical Practice II Reflective Critical Account Abstract**

### **Doing More: The Challenge of Increasing Access to Psychological Interventions in Acute Settings**

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Word Count (including references): 158

## **ABSTRACT**

This reflective account describes my personal responses to the challenges of observing the management of psychological resources with acute mental health services. The account was structured using Rolfe, Jasper and Freshwater (2001) model of reflection. Through this model I reflect on the challenges of working within acute inpatient wards, meeting the demands for psychological interventions and Clinical Psychology's model of working. I then consider why this model of working may have been adopted and what broader issues may have impacted upon changing this. I also consider how Clinical Psychology could modify its model of working in order to promote a higher provision of psychological interventions within the wards and more psychologically minded approaches to patient care. I finally review the reflective process, commenting on how it has highlighted my professional development and how it has affected my future practice.

## **REFERENCES**

Rolfe, G., Jasper, M. & Freshwater, D. (2010) *Critical Reflection in Practice*. 2<sup>nd</sup> edn. London: Palgrave Macmillan.